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# Review of Promising Practices in Services and Supports for People with Developmental Disabilities

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compiled by

The Institute on Disability and Human Development  
The Department of Disability and Human Development  
College of Applied Health Sciences  
University of Illinois at Chicago  
for the Illinois Council on Developmental Disabilities  
January 10, 2005



The following report was compiled “to assist the Illinois Council on Developmental Disabilities in the initial stages of ...preparation for the development of the Council’s new 5-Year State Plan.” The report is a compilation of promising practices that can assist the Council to answer the question “*What would take Illinois to a new and better level in the system of services and supports for people with developmental disabilities?*” (K. Flynn, 2004).

The report examined the following priority areas:

- ☐ Child Care
- ☐ Consumer-Directed Services
- ☐ Education/Early Intervention
- ☐ Employment
- ☐ Family Support
- ☐ Funding Strategies
- ☐ Health/Medical/Dental
- ☐ Housing
- ☐ Leadership Development (family members, self-advocates, and policymakers leaders)
- ☐ Self Advocacy Movement
- ☐ Self Determination (systemic approach rather than project-specific)
- ☐ Transition to Adulthood
- ☐ Transportation
- ☐ Waivers and How Best to Use Them in the Service System Design

The enclosed materials were not meant to be an exhaustive list of initiatives in the states. Rather, they were compiled to stimulate the thinking of members as they consider which topics should be addressed in the upcoming ICDD state plan. Furthermore, the highlighted projects are not meant to be “replicated;” rather, they are meant to encourage the creative thinking of members in their quest to strengthen Illinois’ system for persons with developmental disabilities.



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## INCLUSIVE CHILD CARE

“It is the policy of the United States that all programs, projects, and activities receiving assistance under this title shall be carried out in a manner consistent with the principles that- ...families of children with developmental disabilities need to have access to and use of safe and appropriate child care and before-school and after-school programs, in the most integrated settings, in order to enrich the participation of the children in community life” (DD Act, 2000)

Under the ADA, child care centers cannot discriminate against children with disabilities on the basis of disability. Children cannot be excluded from centers unless their presence “would pose a *direct threat* to the health or safety of others or require a *fundamental alteration* of the program” (DOJ, 1997). Centers must make “*reasonable modifications* to their policies and practices to integrate children, parents, and guardians with disabilities into their programs unless doing so would constitute a *fundamental alteration*” (DOJ, 1997). Furthermore, centers must provide resources for effective communication (such as alternative formats for books) and must comply with physical access requirements.

Key indicators of quality inclusive child care include:

1. “A positive and healthy learning environment”
2. “The right number and mix of children and adults”
3. “Trained and supported personnel”
4. “A developmental focus on the child”
5. “Parents treated as partners” (Brault, Knapp, & Winton, 2004, pp. 6-7).

Benefits of inclusive child care include “enhanced development and well-being for children with special needs; increased acceptance of children with disabilities by children without disabilities; additional support for all parents such as regular communication and opportunities for parent education and family social events; and a positive impact on all parents’ expectations and beliefs about child development and disabilities” (Buysse, 2000).

Inclusive child care initiatives should result in the following four outcomes:

1. Awareness - to be certain that all key stakeholders — those who are, should or could be involved in the development, delivery and improvement of inclusive child care and community services to...families and children...
2. Quality: Identification, development and maintenance of a degree of excellence in care for all children in child care settings, to include those children with disabilities.
3. Collaboration/Accountability: Whole communities, including families, private industries, the religious community and local organizations need to own the need for services to children with disabilities and participate in solving local problems together. Partnerships need to be emphasized between regular and special education, coordination efforts through local coordinating councils, public and private initiatives.
4. Funding: Includes funding that is composed of diverse, varied and flexible resources available at the federal, state and local area to support:
  - Special needs rate
  - Support and consultation services
  - Liability insurance (State of Florida Inclusive Child Care Strategic Plan, 4).



**References:**

- Brault, L. M. J., Knapp, P. & Winton, P. J. (2004). School Readiness for ALL Children: Ensuring that children with disabilities or other special needs are included in California's school readiness efforts. Available at: <http://www.healthychild.ucla.edu/First5CAReadiness/materials/specialNeeds/DisabilitiesBrief.pdf>
- Buyse, M. (2000). Smart Start and Quality Inclusive Child Care in North Carolina Study Highlights. Available at <http://www.fpg.unc.edu/publications/fpggeneral/ssinclusion.pdf>
- The Developmental Disabilities Assistance & Bill of Rights Act of 2000. Available at: <http://www.acf.hhs.gov/programs/add/DDA.htm>
- The State of Florida Inclusive Child Care Strategic Plan (2003). Available at <http://www.centraldirectory.org/uploads/FL%20Inclusive%20Child%20Care%20Strat%20Plan%2012-03.pdf>
- The U. S. Department of Justice, Civil Rights Division. Commonly asked questions about child care centers and the Americans with Disabilities Act. Available at <http://www.usdoj.gov/crt/ada/childq&a.htm>

Some promising practices in the states include:

- ☐ one-to-one “family specialist” mentors (California)
- ☐ strategic planning initiatives (Florida)
- ☐ provider training initiatives (Georgia)
- ☐ evaluations of childcare center compliance with ADA mandates (Guam)
- ☐ cash incentives to providers (Idaho)
- ☐ coordination of a “statewide system of available, accessible, culturally competent, family-centered developmentally appropriate, healthy and safe childcare for children with special needs” (Indiana)
- ☐ statewide collaborative efforts (Maine)
- ☐ inclusive childcare models which embrace positive behavioral supports (Montana)
- ☐ training and technical assistance efforts (Montana)
- ☐ statewide inclusive childcare taskforce (New Mexico)
- ☐ provider rate subsidy programs (Oregon)
- ☐ research on challenging behaviors in childcare settings (Pennsylvania)



**CALIFORNIA (also Family Support)****“The Child Care Inclusion Challenge Project” (San Francisco)**

“The Child Care Inclusion Challenge Project’s (CCICP) mission is to make quality inclusive child care the norm in San Francisco so that each child will have the opportunity to realize his or her full potential.

We support families who have children with special needs in finding and maintaining inclusive child care. In addition, families are provided with information, education and parent-to-parent support. CCICP also offers child care providers on-site consultation, technical assistance and trainings on topics related to working with children with special needs.” <http://www.supportforfamilies.org/inclusionproject/index.html>

This project is a collaboration between the Children’s Council of San Francisco, Wu Yee Children’s Services (a non-profit), Support for Families of Children with Disabilities (a family resource center), and the Child Care Law Center (a nonprofit legal services organization).

“Each Inclusion Project family is assigned a Community Resource Parent Support for Families who works one-on-one with the family to provide individualized assistance. Family Specialists, who are all parents of children with special needs, help the family find, gain access to and maintain appropriate child care. Community Resource Parents who speak Spanish, Cantonese, Mandarin and Tagalog are available to work with families who speak one of these languages at home.

Families of Inclusion Project children have access to a staff attorney at the [Child Care Law Center \(CCLC\)](#), who has expertise in the disability laws (ADA, Section 504) as they intersect with child care.

All services provided by the Child Care Inclusion Challenge Project (CCICP) are free of charge and confidential. CCICP provides services to providers, including:

- Ongoing technical assistance and support;
- Support in maintaining a positive match between providers and families;
- Information on other community resources that may be helpful to both providers and families;
- Opportunity to work one-on-one with a Child Development Specialist and to undergo an individualized needs assessments;
- Opportunity to receive training on the Americans with Disabilities Act (ADA), definitions of inclusion, family and provider experiences with inclusion, and other related topics.” <http://www.supportforfamilies.org/inclusionproject/index.html>

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## **FLORIDA**

### **Strategic Planning Initiative**

“The intent of this initiative is for the key players in child care, disability and other related areas to develop a five-year Strategic Plan that will result in the expansion of quality, affordable and accessible child care services in community-based settings for a wide range of children with disabilities, and would include infants and toddlers, preschoolers and school-aged children. Community-based settings would include child care programs, afterschool care programs and early childhood programs” (Strategic Plan, 2004, p. 1)

There are four (4) Objectives to this Project:

1. To develop a long range strategic plan for building inclusive child care, early childhood and before/after school programs in Florida for children with disabilities.
2. To identify an implementation or tactical plan which presents how the strategies and actions identified would occur and the party(ies) responsible.
3. To build commitment among the involved parties to build inclusive child care, early childhood, and before/after school programs.
4. To build consensus as to the roles of each of the involved parties should play in building inclusion (p. 2).

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The State of Florida Inclusive Child Care Strategic Plan (68 pages)



<http://www.centraldirectory.org/uploads/FL%20Inclusive%20Child%20Care%20Strat%20Plan%202012-03.pdf>

## GEORGIA

### **Task Force on Child Care for Children with Disabilities**

<http://www.ganet.org/gccc/disabilities/execsummary.html>

“Accessible child care was identified as a top priority during the Governor’s Council on Developmental Disabilities’ (hereafter called DD Council) recent needs assessment process. During the time that the needs assessment process was underway, several child care centers that provide services for children with disabilities were forced to close, or have considered closing for economic reasons. The closures highlighted a growing shortage of quality programs that accept children with disabilities. The DD Council’s three-year plan includes a goal to increase the number of children with disabilities and families who have access to quality, appropriate child care.

Consultations with The Georgia Child Care Council and The Division of Public Health’s Babies Can’t Wait Early Intervention (Part C of the Individuals with Disabilities Education Act-IDEA) Program identified mutual concerns about the state of child care for children with disabilities. In November 1998, the directors of the DD Council, Georgia Child Care Council, and Babies Can’t Wait Early Intervention (Part C of IDEA) Program appointed a task force to:

- identify and define the major barriers to inclusive child care in Georgia;
- determine the scope of the problem regarding the availability and accessibility of inclusive child care; and
- recommend strategies to address the major barriers, and identify entities to act on recommendations.

Task force participants included individuals from nearly twenty state public and private agencies and organizations, along with three parent advocacy groups and the parent of a child with disabilities. By establishing the Task Force on Child Care for Children With Disabilities, The Governor’s Council on Developmental Disabilities, The Georgia Child Care Council, and Babies Can’t Wait Early Intervention (Part C of IDEA) Program, took a giant step toward bringing the key player agencies/ organizations’ representatives to the table to determine a long-term, sustained and comprehensive interagency approach to addressing issues related to inclusive child care.” [http://www.ganet.org/gccc/disabilities/Inclusion\\_Project.pdf](http://www.ganet.org/gccc/disabilities/Inclusion_Project.pdf)

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### **SCEIs / Babies Can’t Wait for Childcare Training (also Early Intervention)**

“Under Part C Early Intervention Program standards, each infant and toddler’s services must be provided, to the maximum extent appropriate, in natural environments, including child care and



community settings. The 2000 Natural Environments Survey (Babies Can't Wait) and the Task Force Report on inclusive childcare (GA DD Council, 2000) highlight the need for training and technical assistance for childcare providers to expand the options for inclusive childcare. As of December 2001, 3,512 children were enrolled in Georgia's Part C Babies Can't Wait (BCW) Program. The BCW Continuous Improvement Plan, based on the Self-Assessment report submitted to the U.S. Dept. of Education, indicates a priority need to expand the capacity of Georgia's childcare programs to provide inclusive services. Through this project, IHDD sponsors a series of workshops for center-based and family day care providers to learn strategies to support young children in inclusive childcare settings. Providers gain skills that allow them to feel comfortable and confident in working as a collaborative team member with infants and toddlers with disabilities and their families. This project will contribute to practice by increasing the community capacity to provide inclusive programs as well as foster collaborative efforts between early intervention providers and childcare personnel." [http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=1415&keywords=can%27t%20wait](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=1415&keywords=can%27t%20wait)

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## **GUAM**

"In line with the 2002-2006 Five-Year State Plan Goal that children and families benefit from a range of inclusive, flexible childcare options, the CNMI Council on Developmental Disabilities has awarded a \$13,100.00 to the Guam Center for Excellence in Developmental Disabilities Education, Research & Services (CEDDERS) last November. The purpose of the initiative is to assess all CNMI private day care centers and to assist in disseminating information regarding childcare in the CNMI. In collaboration with the Public School System Childcare Development Fund Program and the Childcare Licensing Agency, Department of Community & Cultural Affairs, the Council through CEDDERS, is task to conduct an ADA accessibility (includes architectural, policies and practices) of up to 12 private day care centers to determine if they are accessible to, and usable by children with developmental (emphasis) disabilities, as well as to assist the CNMI PSS Childcare Development Fund Program in the dissemination of information regarding childcare in the CNMI.

Second, the Council will develop a public awareness informational packet on quality childcare centers and the different options available to families in the CNMI. Additionally, the Council will review and comment on existing and propose Rules & Regulations of the CNMI Childcare License and the PSS Board of Education Child Care Program Administrative Rules, according to Thomas J. Camacho, Executive Director of the CNMI Council on Developmental Disabilities" (<http://www.cnmiddcouncil.org/subsite4/councilbodies/childcareproject2body.htm>)

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## IDAHO

### IdahoSTARS

“IdahoSTARS is Idaho’s State Training And Registry System. They are the state’s Child Care Resource and Referral administrative agency, focused on improving the quality, affordability, and accessibility of child care in Idaho. IdahoSTARS maintains the [Professional Development System](#), a career pathway and provider database that aims to help providers advance in their careers and keep learning. IdahoSTARS provides trainings, scholarships, mentorships, and cash incentives to help providers improve the quality of their practice. They also maintain a database of child care providers in the state and refer parents to providers that match their needs. IdahoSTARS is working with the UCEDD for the state of Idaho on this project.” [www.idahocdh.org](http://www.idahocdh.org)

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## INDIANA

### The Indiana Partnership for inclusive child care (IPICC)

“Data from a variety of sources indicates that families of children with developmental disabilities in Indiana have a number of unmet childcare related needs. To improve this situation, the Riley Child Development Center (RCDC) at the James Whitcomb Riley for children and the Indiana Association for Child Care Resource and Referral (IACCRR) will be at the primary coordinating agencies for this collaborative project, entitled The Indiana Partnership for inclusive child care (IPICC). This project proposes to develop a model, inclusive childcare system for organizing consumers and providers at the community level. IPICC will coordinate a statewide system of available, accessible, culturally competent, family-centered, developmentally appropriate, healthy and safe, childcare. Emphasis will be placed on providing supports, training and technical assistance for enhanced integration and coordination of existing community-based childcare services. The project will also include the quantity and quality of care available to all children. The project will also increase retention of childcare providers and ensure consistency, thus increasing stability of care and continuity of services for children with developmental disabilities. Over a three-year period, across all ninety-two Indiana counties children with developmental disabilities and special needs and their families will benefit from improved childcare support and services. The project will utilize a variety of techniques and strategies to enhance the quality and inclusiveness of Indiana’s child care system. The project will include resource and referral services to families, training and technical assistance to providers, families, and the community at large, as well as innovative distance learning technologies for outreach to underserved areas. Materials and procedures developed by the project will be incorporated into manuals and CD-ROM’s and made available on the web. Dissemination will be accomplished through publications, state and national conference presentations, videoconference presentations and a dedicated Internet website. The project will be constructed to allow replication by other states, thus enhancing and increasing inclusive childcare in communities across the nation. The project will draw upon the strengths and systems in place at the local/community level, and create a solid infrastructure for families and providers, to ensure quality of care for all children. The



specific Project of National Significance (PNS) priority addressed by IPICC is child care related activities, and which will have complementary effects on other PNS priorities as follows: improving quality, assisting; in early identification of children with disabilities and delivery of early intervention services, as well as improving the health and safety of all child care facilities.

This project proposes to develop a model inclusive childcare system for organizing consumers and providers at the community level. It will coordinate a statewide system of available, accessible, culturally competent, family-centered developmentally appropriate, healthy and safe childcare for children with special needs. Emphasis will be placed on providing support, training, and technical assistance for enhanced integration and coordination of existing community-based child-care services. The project will deliver resource and referral services to families, training, and technical assistance providers, the community at large, as well as outreach to other underserved areas. Materials and procedures developed by the project will be incorporated into manuals and CD-ROMs and made available on the web.” [www.aucd.org](http://www.aucd.org) NIRS database

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## **MAINE**

### **Child Care Plus Maine Project**

“The University of Maine Center for Community Inclusion and the Department of Human Services Office of child care and Head Start continue to implement the child care Plus Maine Project. The focus of this project is to develop a system of support for care and education providers so that they have the skills, knowledge and resources to care for all children including children with challenging medical and behavioral health care needs.

The model addresses the need to work at the community level with care and education providers, at the regional level with existing child care, education, early intervention, health and mental health systems and at the state level with State of Maine departments, offices and agencies so that a comprehensive system can be designed to ensure that all children have access to quality community care and education and parents can work.

Activities to improve the quality of early care and education and school age child care for children with disabilities or other special needs during this period include work with the project’s collaborative partners including the Bureau of Family Independence, Bureau of Health, Center for Community Inclusion and the Office of child care and Head Start as well as with other State of Maine Departments and relevant regional stakeholders. Specific work includes 1) the review of policies, procedures and materials to guide the project and promote enhanced understanding of and access to these services; 2) assistance to State and local child care resource and referral agencies, licensing agencies and others on compliance with the Americans with Disabilities Act of 1990, the Individuals with Disabilities Education Act, and section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794) and other information to ensure that they are providing the information and services necessary to promote quality inclusive child care and; 3) the identification of interagency/



departmental policies and creative funding strategies to expand the capacity of child care providers to care for children with special needs. Areas of systemic focus include the examination of and work to develop a child care health nurse system and an expansion of mental health support to early care and education and school age child care providers.” [http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=294&keywords=child%20care%20plus%20maine](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=294&keywords=child%20care%20plus%20maine)

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## **MONTANA (also Education/Early Intervention)**

### **Keeping Everyone in Early childhood Programs (KEEP)**

“KEEP is designed to develop, implement, and evaluate a model for using progressive, positive behavioral supports to maintain early childhood placements for children with disabilities and behavior challenges. The model presents a continuum of support which includes a (1) base of high quality, developmentally appropriate practices, (2) a set of core behavior beliefs and strategies which create a positive approach to guidance, and (3) specialized intervention strategies and techniques which can be used for children whose behavior creates significant challenges in the typical early childhood setting.

The goal of the project is to develop, implement, and evaluate a model for using progressive, positive behavioral supports to maintain early childhood placements for children with disabilities and behavior challenges. KEEP offers a model for inclusion which incorporates three levels of support to child care providers: (1) Quality Practices; (2) Core Behavior Strategies and Beliefs; and (3) Special and Individualized Supports. The project uses the existing child care infrastructure and builds on services currently in place in the community. Eight key characteristics are identified:

- Individually & Developmentally Appropriate Practices
- Model Development & Demonstration in Community-Based child care Programs
- Family Centered care
- Extensive Training & On-Site Technical Assistance
- Use of Progressive and Positive Behavioral Supports which are Specifically Designed for child care
- A Demonstration Site For Training & Programs Dissemination
- Coordinated Delivery of Existing Services & Resources

Project staff will develop and implement the model in seven community-based child care programs including two family child care homes, two group child care homes, two child care centers, and one after school program associated with a preschool special education program. These programs are located in Missoula, Ravalli, and Mineral Counties. The project will serve a total of approximately 125 children including ten with disabilities or significant behavior disorders and fifteen to twenty with behavior challenges reported by the child care program staff” ([http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=1173&keywords=keep](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=1173&keywords=keep)).



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**MONTANA (also Education/Early Intervention)****Statewide Inclusion Resources and Training**

[http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=1225&keywords=inclusive](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=1225&keywords=inclusive)

The overall goal for “Statewide Inclusion Resources and Training” is to strengthen Montana’s child care system to more effectively support the needs of children with disabilities and their families. The project includes the following major components:

- Provide training and technical assistance to child care providers through on-site visits, telephone consultation, formal training sessions, the Internet, and self-study course activities.
- Support trainers in embedding inclusion in existing training opportunities by providing technical assistance and training to trainers including a fifteen-hour self-study course for trainers.
- Collaborate with early intervention and related service providers by providing technical assistance to service providers, developing training materials for these professionals, and facilitating links to local CCR&R agencies.
- Educate families, child care providers, and family support specialists about how to include child care services in Individualized Family Service Plans and Individualized Education Programs through training and technical assistance activities and the development of a new training product on this topic.
- Collaborate with child care Resource and Referral agencies to insure that referral services are available to families of children with disabilities throughout the state and that Best Beginnings scholarships are readily available to eligible families.
- Collaborate with other service providers and resources who work with children with disabilities and their families within Montana as well as throughout the country.
- Provide consultation and training for child care providers to help them implement—and sustain the spirit of—the Americans with Disabilities Act.
- Bring innovation to Montana’s child care system by monitoring national trends, resources, and products.
- Collaborate with state level partners in the development and implementation of policies and practices that promote inclusive child care environments.
- Help promote increased access to inclusive child care resources.



- Provide information about the project, inclusive child care, and related issues via statewide newsletters, the project's web site, and dissemination of products.
- Track progress and document lessons learned to explore the need for future support of inclusive child care efforts.

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## **NEW MEXICO**

### **Inclusive Childcare Statewide Taskforce**

“In January of 2004, the New Mexico Children Youth and Families Department (CYFD) asked the CDD to partner in developing recommendations for the implementation of inclusive childcare in our state. This effort was to be carried out with a Statewide Taskforce that would explore the issues, craft recommendations, and provide guidance to CYFD as it continues to pursue high quality, early care opportunities for New Mexico's children and families.”

“The purpose of this Contract is to provide professional services to the Office of Child Development & Child Care Services Bureau to:

1. Develop a plan for establishing inclusive child care through an enhanced rate and service structure; and,
2. Develop a plan for providing training and consultation to child care providers to better serve children with special needs in inclusive settings.

The Center shall convene, facilitate, and document twelve (12) meetings of an inclusive child care Task Force that is to meet at least half a day, two times per month, consisting of Early childhood Interagency Action Team (ECIAT) members and other stakeholders, such as representative parents, providers, and advocates as determined in cooperation with the Department in order to establish a vision for providing a range of appropriate, inclusive child care services for children with special needs” ([http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=5548&keywords=task%20force](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=5548&keywords=task%20force))

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**OREGON****Partners for Inclusive Child Care (PICC) Pilot Project**

[http://www.ocdd.org/pdfs/openheart\\_eng.pdf](http://www.ocdd.org/pdfs/openheart_eng.pdf)

“The Oregon DD Council manages the program and project under a contract with the state’s Child Care Division. The core service of the Inclusive Child Care Program is a supplemental subsidy to meet higher costs of care related to a child’s special needs. [They] also work closely with the state’s child care subsidy program, and with a number of other agencies and advocates on issues related to child care and children with disabilities (all types: developmental, emotional/behavioral, medical, etc.)”.

“The PICC Pilot Project seeks to increase community capacity for quality child care in typical, inclusive child care and out-of-school time settings. “Capacity” is defined as services and resources such as resource and referral, provider training, consultation and other resources that make child care accessible, stable, and inclusive.” “The PICC Pilot Project will help make inclusive child care training, one element of community capacity, available in four selected communities. It will do this by fully funding 8 individuals to become trainers in Western Oregon University’s TRAC (Teaching Research Assistance to Child Care Providers) inclusive child care curriculum. In addition, the project will provide partial funding to support TRAC training to child care providers in the community. It is expected that additional supports to training will come through community partners.” “It is not the intent of the project to support a “stand alone” training opportunity. Rather, it is a core principle of this pilot project that training must be accompanied by individualized, coordinated follow up supports. Therefore, applicants were asked to identify community resources, such as individualized consultation for child care providers, and to link these resources to TRAC trainings for ongoing supports to inclusive child care placements” (email from Terry Butler).

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## **PENNSYLVANIA**

### **Managing Challenging Behaviors**

“Child care providers and early intervention specialists need more education and training on handling challenging behaviors in children developing typically and children with disabilities. These behaviors often are the main reason that children with disabilities are unable to continue in inclusion settings.

This project will create before and after video tapes showing the challenging behavior and the amended behavior, respectively. Accompanying the videos will be a corresponding workbook with strategies and tips in dealing with and redirecting this behavior. The project will include prevention as well as management strategies for child care providers and the families they serve.

It is the goal of this project to aid child care providers with instruction in behavior modification techniques. Through intervention the child will learn inclusive behavior that will aid in the success of the child’s academic career.” [www.aucd.org](http://www.aucd.org) NIRS database

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## **CONSUMER-DIRECTION**

Nationally and internationally, policies promoting the self-determination of individuals with disabilities and their families are increasing. Most notably, models of consumer-direction have emerged that provide individuals and families with control of resources to design and direct their supports. Reviewing consumer-directed models within the United States, Powers (2003) highlights the following general characteristics:

- a) authority and accountability of the service customer;
- b) individualized, customer-directed service planning;
- c) customer selection, training, and supervision of support providers;
- d) limited oversight by medical providers;
- e) flexible benefits that include personal assistance, assistive devices, environmental modification, customer education, support brokers, fiscal intermediary and employment supports;
- f) individualized funding of service plans through cash payments to customers or customer authorization of service payments by a funding agency or fiscal intermediary; and
- g) customer definition and monitoring of service quality

Various models that have emerged include: 1) Providing vouchers to individuals for the purchase of authorized services; 2) Providing individualized budgets and brokered support, where fiscal intermediaries provide payments for supports and services; and 3) Providing cash benefits directly to individuals with the option of technical assistance –also known as “cash and counseling.” (Powers, 2003; Simon-Rusinowitz et al., 1997).

The current trend regarding consumer-direction is the Independence Plus waiver template. This template is a result of the Cash and Counseling Demonstration Projects done in Florida, Arkansas, and New Jersey and funded through the Robert Wood Johnson foundation (Mahoney et al., 2002; Simon-Rusinowitz et al., 1997; Simon-Rusinowitz et al., 2001). Individuals were provided a cash option to direct their own services, versus traditional services provided through agencies. The research on the demonstrations has shown many positive outcomes including higher satisfaction with services. Due to the success of the projects, CMS developed the Independence Plus waiver template to make it easier for states to develop similar waivers. Essentially the waivers are either 1915c (Home and Community Based) or 1115 (Demonstration). A handful of states have so far developed Independence Plus waivers and several others are in the process. Three states were selected as promising practices. Ohio is in the process of developing an Independence Plus waiver, Louisiana is one of the first states to develop an Independence Plus waiver for individuals with developmental disabilities and is slowly phasing it in, and Florida has chosen to use the 1115 demonstration option.

## **References**

- Mahoney, K.J., Desmond, S.M., Simon-Rusinowitz, L., Loughlin, D.M., & Squillace, M.R. (2002). Consumer-preferences for a cash option versus traditional services: Telephone survey results from new jersey elders and adults. *Journal of Disability Policy Studies*, 13(2), 74-86.
- Powers, L.E. (2003). Self-Determination and Person-Directed Support. Paper presented at the 2003 National Conference on Self-Determination for Mental Health Consumers/Survivors, October 2003.



- Simon-Rusinowitz, L., Mahoney, K., Desmond, A., Shoop, D., Squillace, M., & Fay, R. (1997). Determining consumer preferences for a cash option: Arkansas survey results. *Health Care Financing Review*, 19 (2), 73-96.
- Simon-Rusinowitz, L., Mahoney, K.J., Shoop, D.M., Desmond, S.M., Squillace, M.R., & Sowers, J.A. (2001). Consumer and surrogate preferences for a cash option versus traditional services: Florida adults with developmental disabilities. *Mental Retardation*, 39(2), 87-103.

## **FLORIDA (also Waiver)**

### **Independence Plus 1115 Demonstration**

Florida is the first state to develop and Independence Plus Waiver through the route of an 1115 demonstration waiver. Since it is a demonstration waiver there is theoretically even more flexibility for states to develop consumer-directed waivers than the traditional 1915c Home and Community Based waiver. It also allows states more flexibility in the types of services provided. The waiver developed by Florida cuts across different categories of disability. It includes individuals with physical disabilities (both young and older), traumatic brain injury, and children with developmental disabilities. A previous state waiver, that was part of the Cash and Counseling demonstration project, was amended and expanded statewide. Since Florida is the first state to develop a 1115 demonstration waiver under the Independence Plus initiative it can serve as a model for other states.

For more information:

<http://www.cms.hhs.gov/medicaid/1115/flcdcipamdappran.pdf> (CMS)

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## **OHIO (also Waiver)**

### **Department of MR/DD Independence Plus Initiative**

The Ohio Department of MR/DD received a systems change grant from the Centers for Medicaid and Medicare Services (CMS). This is a three-year grant to put systems of consumer-direction in place using the Medicaid waiver program and the new Independence Plus waiver template. Ohio is a county-based state, versus the regional nature of the system in Illinois. The Independence Plus grant will allow the Ohio Department of MR/DD to work with county boards of MR/DD and other stakeholders to establish the federal expectations set forth by CMS. This will lead to the development and implementation of a self-directed waiver. The federal expectations include a person-centered plan, individual budget, fiscal management services, support brokerage, incident tracking system, and an emergency back-up system. Twenty-one of the 88 county boards are participating. Each county is forming a work group. Each team consists of the Superintendent, Director of Adult Services, Director of Service and Supports Administrators, Business Manager and a representative of private providers, people with a disability and family members. Work groups identify potential barriers and solutions and report to the state. At the state level, there is an advisory



board made up of people who can help with obtaining technical assistance from CMS or other experts and taking concerns to the state officials who are needed to address recommendations. The advisory board will work with the Ohio Department of Job and Family Services to make necessary changes to state law and administrative code. The ultimate goal of the initiative is to apply for an Independence Plus waiver and implement it in at least five counties in Ohio.

For more information:

[http://odmrdd.state.oh.us/Includes/SelfDetermination/SelfDet\\_Init.htm](http://odmrdd.state.oh.us/Includes/SelfDetermination/SelfDet_Init.htm) (Ohio Department of MR/DD)

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## **LOUISIANA (also Waiver)**

### **New Opportunities Waiver**

Louisiana developed one of the first Independence Plus Waivers specifically for individuals with developmental disabilities. Since Louisiana, like Illinois, is not thought of as a traditional leader in the field of developmental disability services it might be a good model to follow. They are moving slowly with a phase in process that will slowly give current waiver individuals the option of self-direction. The waiver covers a wide range of supports and services such as respite, residential and day habilitation, supported employment, community integration development, environmental adaptations, and professional services. The waiver was approved in April of 2003 and has a 3-year phase in period. The Bureau of Community Supports and Services, a separate division within state will operate the waiver. They will use person-centered planning, individualized budgets, and support brokers. They also plan to contract with a fiscal intermediary to handle processing, compensation, and tax issues.

Activities include:

- “Create an Independence Plus Advisory Committee (IPAC) whose primary responsibility will be to oversee the project and guide the systems change process.
- Analyze policies and procedures manuals and fiscal procedures for the three targeted waiver programs, and recommend revisions to language to incorporate the philosophy of self-determination.
- Train agency staff and stakeholders on principles of self-determination.
- Identify best practices regarding back-up systems and modify the state’s back-up system for all targeted waivers. Conduct training on the use of the revised back-up support systems.



- Recruit providers willing to offer back-up support to waiver recipients who have chosen self-direction and/or are using a fiscal agent.
- Establish a revolving loan fund and policies and safeguards for the use of these funds.
- Conduct regional training for micro-enterprise developers, self-advocates and family members, providers, and case managers to help individuals determine what type of business they would like to have, develop a plan for that business, and explore resources for implementation.
- Recruit 27 waiver participants from the three targeted waivers help them establish micro-enterprises, which will expand opportunities for them to earn income, own businesses, and increase their contribution to the cost of their care.
- Collect and analyze data to assess the impact of incorporating self-determination principles into the three target waivers.” <http://www.hcbs.org/files/31/1539/LAip03.htm>

For more information:

<http://www.cms.hhs.gov/newfreedom/528lanow.pdf> (CMS)

<http://www.hcbs.org/files/37/1846/laip.htm>

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Supplemental Readings:

<http://www.kff.org/medicaid/4151.cfm> (Kaiser Family Foundation -overview of Independence Plus)

<http://www.hcbs.org/files/42/2099/Guidefront.pdf> A guide to quality in consumer directed services



## EDUCATION/EARLY INTERVENTION

The DD Act defines early intervention activities as “activities provided to individuals described in paragraph (8)(B) and their families to enhance—

- (A) the development of the individuals to maximize their potential; and
- (B) the capacity of families to meet the special needs of the individuals.” (DD Act, 2000)

Benefits of early intervention include: “child development and functioning, child quality of life, and parenting competence and confidence” <http://ericec.org/osep/newsbriefs/news33.html>

Education activities are defined as “activities that result in individuals with developmental disabilities being able to access appropriate supports and modifications when necessary, to maximize their educational potential, to benefit from lifelong educational activities, and to be integrated and included in all facets of student life.” (DD Act, 2000)

“On January 8, 2002, President Bush signed into law the No Child Left Behind (NCLB) Act of 2001...NCLB champions accountability for “all students, including student groups based on poverty, race and ethnicity, disability and limited English proficiency.”

This legislative act contains four basic education reform principles:

- stronger accountability for results;
- increased flexibility and local control;
- expanded options for parents; and
- emphasis on teaching methods that have been proven to work. (National Center on Educational Outcomes, 2003).

Through NCLB, states must implement statewide accountability systems covering all public schools and students (Pasternack, 2003). According to the National Center on Educational Outcomes, the main difference between IDEA and NCLB is that the former specifically governs services that are provided to students with disabilities and provides individual accountability through IEPs developed on the basis of each child’s unique needs. The National Center believes that NCLB complements the IDEA provisions by providing public accountability at the school, district, and state levels for all students with disabilities. Secondly, NCLB builds on IDEA law by requiring the participation of students with disabilities in state and district-wide assessments (National Center on Educational Outcomes, 2003).” (National Council on Disability, 2004)

The National Center on Education Outcomes assists states with their assessments. Martha Thurlow, Director of NCEO, identified three states as exemplary in this area: Kentucky, Massachusetts, and Ohio.

### References:

- American Youth Policy Forum & Center on Education Policy.(2002).*Educating Children with Disabilities* .Washington, DC.
- The Developmental Disabilities Assistance & Bill of Rights Act of 2000. Available at: <http://www.acf.hhs.gov/programs/add/DDA.htm>



- National Center on Educational Outcomes.(2003).*Accountability for assessment results in the No Child Left Behind Act: what it means for children with disabilities*. Minneapolis, MN: University of Minnesota, National Center on Educational Outcomes.
- National Council on Disability. (2004). *Improving Education Outcomes for Students with Disabilities*. Washington, D.C.
- Pasternack,R.(2003).*No Child Left Behind. A powerpoint presentation*. Washington, DC: U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

## KENTUCKY

The state of Kentucky makes the assessment available online for all students with disabilities so they can use text talk or talk to text. Every classroom throughout the state has computers and internet access. Also, according to Margaret Reed (Kentucky Department of Education), Kentucky is one of only two states in the nation with all of their students in the accountability system. They surpass other states in terms of inclusive programs and inclusive environments. Furthermore, all of Kentucky's special education teachers are dual certified (i.e., with a regular education certificate as well). Finally, they have an intern/trainee program for special education teachers (Margaret Reed, personal communication, 2005). For more information visit the website:

[www.education.ky.gov](http://www.education.ky.gov)

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## MASSACHUSETTS

### Project Focus

“The educational challenges facing students, parents, teachers, and administrators in school districts across Massachusetts signal the need to develop a comprehensive framework for change and improvement that encompasses existing initiatives as well as key stake holders. The Massachusetts Education Reform Act of 1993 aimed at a common goal: an education system that fully addresses the abilities and needs of students and improves post-secondary outcomes for everyone, including students with disabilities. This dynamic vision of education sets high, interdependent standards for the Commonwealth. The Massachusetts Department of Education (DOE) has worked in partnership with a host of child-serving agencies, local school districts, parents, individuals with disabilities and their families, teachers, Institutes of Higher Education, and service organizations to develop Project FOCUS.

Project FOCUS proffers the following outcomes to guide statewide efforts toward systems improvement for the benefit of all students:

- Knowledgeable parents and service providers working together to provide high quality early intervention and preschool services within natural environments for infants and toddlers.
- Knowledgeable parents and educators working together to ensure that all students (K-12) have access to the general curriculum, are supported across all education settings, and are



able to demonstrate their acquired knowledge as full participants in every aspect of Education Reform, including a variety of options for improved postsecondary outcomes.

- Restructured teacher preparation and professional development programs to incorporate promising practices of teaching and learning for students with diverse abilities and needs, based on education reform standards, including strengthening ties among pre-service programs, school districts and local communities.
- Enhanced accountability procedures at the state and local level for students, parents, and educators.

Project FOCUS is designed to provide pre-service and professional development activities for educators, parents, students, and other interested stakeholders. The major themes of parent collaboration, research to practice, interagency coordination, innovation, capacity building, and linkages to existing activities to maximize community, state, and federal resources are reflected across activities in these six focus areas:

1. The first focus area prepares providers and parents to understand and implement a shift in the provision of services and supports to natural environments during early intervention and preschool years.
2. The second focus area, kindergarten and elementary ages, prepares teachers and parents with skills related to ensuring access to the general curriculum in general education settings for all students, with an emphasis on literacy skills (including Braille literacy), universal instructional design to accommodate diverse learning styles, and issues related to the educational climate. The focus on access to the general curriculum will emphasize the Massachusetts Curriculum Frameworks and related content standards using teaching methodology that reflects research-validated practices such as transdisciplinary planning, problem-based learning, integrated technology and SCANS competencies.
3. The third focus area will maintain the same content as the second focus area adjusted to respond to the needs of older students and the generally different administrative and organizational features of middle schools and high schools,
4. The fourth focus area will address enabling students with disabilities, ages 18-22, to participate in adult options, including postsecondary education and employment, with their nondisabled peers.
5. The fifth focus area will assist teacher preparation programs statewide to restructure and unify curricula based on education reform standards and teaching methodologies to prepare general and special educators and paraprofessionals to work with all students within the context of a professional development school model.
6. The sixth focus area will develop and enhance existing accountability systems across the full range of services for infants, toddlers, and students with disabilities.

The Comprehensive System of Personnel Development (CSPD) advisory committee, composed of representative parents, students, educators, and other interested stakeholders will guide project activities” <http://www.doe.mass.edu/sped/projectfocus/abstract.html>.

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Other promising practices in the states include:

- ☐ Educational strategies for inclusion – “Project Participate” (Colorado)
- ☐ Model of early intervention using home activities and play (Colorado)
- ☐ Literacy software (Colorado)
- ☐ Integration of early education and adult literacy (Idaho)
- ☐ Teaching Head Start teachers strategies of Positive Behavior Support (Kansas)
- ☐ Training parents as early intervention coordinators (Maryland)
- ☐ Center that expands educational opportunities through the development and innovative use of technology – “CAST” (Massachusetts)
- ☐ Statewide Community Education Network on Disability for adults (Minnesota)
- ☐ Parent Advocacy Coalition for Educational Rights with a parent training and information center (Minnesota)
- ☐ Program to decrease truancy and dropout rates of student with disabilities - “Check & Connect” (Minnesota)
- ☐ Inclusive post-secondary program (Virginia)
- ☐ National Information Center for Children and Youth with Disabilities



**COLORADO****Project Participate**

“Project Participate provides families, educators, administrators and therapists with simple strategies to increase the active participation of students with disabilities in school programs. Supported by a U.S. Department of Education grant (H324M980258), Project Participate facilitates team collaboration and promotes the appropriate uses of technology in the classroom.”

“...To maximize each pupil’s participation we need to evaluate the child’s ability to take part in school activities and to identify conditions that impede participation. The standard against which a child’s participation is compared is that of a child of similar age without disability in school. Participation is considered to be restricted when there is a discrepancy between the observed participation by a student with a disability and the expected participation of another youngster without a similar disability.

When participation is low, interventions are designed to remove barriers or provide facilitators to increase participation (Rosenberg & Robinson, 1989; Rosenberg et al, 1992). Strategies used to increase participation are very diverse, ranging from high and low tech assistive devices, adaptation of activities, to changing society attitudes that limit participation.” <http://www.projectparticipate.org>

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**COLORADO****ENRICH: Enrichment using Natural Resources in the Community and Home and  
HAPI: Home Activity and Play Intervention**

“The ENRICH’s Home Activity and Play Intervention model (ENRICH/HAPI) of early intervention promotes inclusion by providing family-centered services to young children with developmental disabilities and their families in their homes and other community settings. ENRICH/HAPI draws upon two complementary approaches to early intervention: Transdisciplinary Play-Based Intervention (TPBI) and the ENRICH Project.

Both programs have focused on finding opportunities for learning through daily activities, supporting family-centered practices, and utilizing a transdisciplinary team model. The focus of these services is to foster the child’s independence and active participation in everyday routines (mealtime, bath time), activities (play) and places (playground, pool) by working together with families to identify their priorities and concerns. If children already receive therapy services, ENRICH/HAPI partners with other professionals to help connect therapy ideas to everyday life.

The HAPI Project examines the efficacy of the ENRICH/HAPI model of service delivery for infants and toddlers with disabilities compared to other service delivery models. Pre- and post-data is being



collected for the two groups for the following areas: child independence, child coping effectiveness and parent-child interactions.

Major Goals:

1. Develop, implement and evaluate a service delivery model of early intervention for young children with developmental disabilities and their families utilizing resources in their community and focusing on life situations and daily routines;
2. Increase independence and active participation of children with developmental disabilities in everyday routines, activities and places;
3. Provide a milieu of family/team collaboration to generate strategies based upon the families' priorities and concerns."

<http://jfkpartners.org/ENRICH.Asp>

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## COLORADO

### **The CSLR Reading Project (for students with learning disabilities & autism)**

"The CSLR Reading Project is a component of the [Colorado Literacy Tutor](#), a collaboration between universities and public schools that aims to improve student achievement through development of educational software that helps students learn to read and comprehend text. The Colorado Literacy Tutor consists of two main projects, *Foundations to Literacy*<sup>™</sup>, or FtL<sup>™</sup>, a comprehensive, scientifically-based and individualized reading program that uses a virtual tutor to teach students to read and learn from text, and Summary Street, a program that uses Latent Semantic Analysis to grade students' summaries of text and provides feedback that helps them revise and improve their summaries.

A key objective of the CSLR Reading Project is to improve human communication technologies through basic research, leading to the invention of perceptive animated agents- lifelike computer characters that speak, emote and gesture, and engage learners in natural face-to-face conversations in learning tasks, much like effective and sensitive teachers. By embedding perceptive animated agents in immersive, multimedia learning environments, we hope to improve student achievement by teaching foundation reading skills (e.g., phonological awareness, sounding out words), fluent reading and comprehension. Inventing perceptive animated agents involves integrating research advances in areas of speech recognition, natural language understanding, computer vision and computer animation." <http://cslr.colorado.edu/beginweb/reading/reading.html>

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**IDAHO****Even Start Family Literacy Project**

“Even Start is an education program that is designed to improve the academic achievement of parents and their young children, especially in the area of reading. Young children who have good vocabularies and who are taught early reading skills before they start school are more likely to become good readers and achieve academic success throughout their school careers.

Parents play a critical role in the language and intellectual development of their children. Children who have parents who talk and play with them and who read to them have an important advantage. And parents who themselves are competent readers are more likely to have good jobs and be able to help their own children in school.

The Even Start program integrates early childhood education, adult literacy (adult basic and secondary-level education and/or instruction for English language learners), parenting education and interactive parent and child literacy activities into a single, unified family literacy program.

The Even Start Family Literacy Program, funded by the Idaho State Department of Education, promotes family literacy by:

1. Supporting parents in the educational growth of their children.
2. Offering assistance with Adult Basic Education (ABE), General Equivalency Diploma (GED), or English as a Second Language (ESL).
3. Preparing children for success in life through early childhood education programs.
4. Preparing adults for success in the workplace.”

<http://www.idahocdhed.org/evenstart/family.htm>

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**KANSAS****Head Start Positive Behavior Support Project**

“Developing effective interventions to address challenging behavior is an ongoing process in early childhood programs. Identifying interventions that can be successfully used in early childhood education settings to decrease the challenging behavior of children while increasing social competence should increase the probability that children will be successful in their educational experiences as well as in their future daily lives. Positive Behavior Support (PBS) is one approach that has produced successful outcomes for children with disabilities who engage in challenging behavior, and is now being successfully implemented with typically developing children. PBS is built on the foundation of preventing problem behavior through environmental arrangement, effective teaching and programming, as well as individualized interventions for those children who engage in more serious forms of challenging behavior. PBS represents a comprehensive, systematic



approach that requires a high level of commitment from staff and administrative support to be successful.

The Head Start Positive Behavior Support Project is designed to teach Head Start teachers and staff the principles of PBS and encourage their implementation of PBS strategies in Head Start Centers. SEK-CAP Head Start has devoted considerable resources to developing a program-wide PBS system that is being implemented in 15 centers across Southeast Kansas. This project will include a participatory approach wherein teachers, program coordinators, and University personnel will work collaboratively to accomplish the project objectives. The project's goals include 1) Developing a training program in PBS for all Head Start staff, 2) Building a system of support for staff through team training, monthly follow-up, and ongoing consultation in PBS, 3) monitoring the effectiveness of this model for implementing PBS in early childhood settings. By developing internal expertise in using multiple strategies to promote positive behavior in all children enrolled. Head Start staff can engage community partners in developing cross-disciplinary strategies related to individual child needs. The project objectives and activities should directly benefit the children who may display challenging behavior, while increasing socially appropriate behaviors as well as their overall social competence. The participating Head Start program will also benefit by increasing the teachers' and staff knowledge and skills, and through the enhancement of local resources to promote social competence. Additionally, the project activities should add to the growing knowledge base in the areas of social competence, prevention of challenging behavior, and the implementation of positive behavior support in early childhood settings." [www.aucd.org](http://www.aucd.org) NIRS database

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## **MARYLAND**

### **New Vision: Training Parents as Early Intervention Coordinators**

"A complete curriculum that contains all of the resources and materials needed to successfully prepare "veteran" parents to provide early intervention service coordination to families whose infants and toddlers are eligible for services under Part C of the Individuals with Disabilities Education Act (IDEA). The training package emphasizes family-centered approaches and recognizes that parents of children with disabilities are uniquely qualified to serve as early intervention service coordinators (case managers) when provided with additional training and support. Includes the Project Copernicus Train-the-Trainer Series." [www.qualitymall.org](http://www.qualitymall.org)

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**MASSACHUSETTS****CAST—Center for Applied Special Technology**

“CAST is a not-for-profit organization whose mission is to expand educational opportunities for individuals with disabilities through the development and innovative uses of technology. CAST believes that the most effective strategy for expanding educational opportunities for individuals with disabilities is through Universal Design for Learning. Their work focuses on the development of learning models, approaches, and tools that are usable by a wide range of learners.

CAST provides national leadership in Universal Design for Learning (UDL) through its leadership role in the National Center on Accessing the General Curriculum, publications, presentations, and participation in national forums related to education. CAST also develops and releases educational products, including tools and learning supports that are designed according to the principles of UDL and conducts research, professional development, and curriculum planning support in schools and educational settings.” [www.qualitymall.org](http://www.qualitymall.org)

CAST—Center for Applied Special Technology

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<http://www.cast.org>

**MINNESOTA****Community Education Network on Disability**

“The Community Education Network on Disability (CEND) in Minnesota represents 37 programs throughout the state that offer customized classes and activities, as well as inclusion services, for adults with disabilities. The programs reflect the uniqueness of their own communities and work hand in hand with providers, families and schools in their communities to offer programming that is valuable, safe, enjoyable, affordable and reflects the interests of the consumers. Some programs also offer support groups and workshops for families/caregivers and professionals about disability topics. Most programs also participate with local Family Collaboratives and with the Community Transition Interagency Committee’s in Minnesota that coordinate school and community-based services available for youth and young adults with disabilities. Programming and services are available to any adult (or in some places older youth) with any disability. Often times individuals with developmental disabilities choose to attend the customized classes while other individuals might choose to request inclusion services for district community education. All programming is responsive to the needs and wishes of the consumer with evaluations and yearly surveys conducted by the programs.”

[www.qualitymall.org](http://www.qualitymall.org)

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<http://www.isd742.org/CEND/index.htm>

<http://www.isd742.org>



**MINNESOTA (also Transition)****Parent Advocacy Coalition for Educational Rights (PACER)**

“PACER was founded in 1977 with a “mission is to improve and expand opportunities that enhance the quality of life for children and young adults with all disabilities; physical, mental, emotional, learning; and their families.” PACER offers a number of programs to reach this mission. PACER’s programs help parents become better advocates for their children of all ages through increased knowledge about laws, resources, and parents’ rights and responsibilities.

PACER is funded under the Individuals with Disabilities Education Act (IDEA) as the Parent Training and Information Center for Minnesota. There is a similar center in every state with a mission to support and advocate with parents of children with disabilities. PACER was among the first of these centers and is one of the largest. PACER now receives funding from the United States Department of Education to provide technical assistance to smaller and less developed Parent Training and Information Centers operating in other states.

Currently, PACER’s programs for parents include: Parents Helping Parents Program, American Indian Parent Network, Early Childhood Project, Project for Parents of Children with Emotional/Behavioral Disorders (EBD), Grandparents Program, Multicultural Project, Project PRIDE (PACER’s Rehabilitation Act Information & Disability Education), Project Youth, Transition and Natural Supports in the Workplace, and the Health Information and Advocacy Center.

PACER also provides programs for students, schools and professionals. These include: Family Strengths Program, Let’s Prevent Abuse Program, Risky Situations: Vulnerable Children, Computer Resource Center, COUNT ME IN Disability Awareness Puppet Program, Juvenile Justice Training Program, Minnesota Parent Center (formerly FAST Forward: Families and Schools Together), Project KITE (Kids Included through Technology are Enriched).

The third category of PACER programs provide technical assistance to help parents and agencies in realizing the intents of state and federal laws concerning special education programs. These programs include: Technical Assistance Alliance for Parent Programs, TATRA (Technical Assistance on Transition and the Rehabilitation Act).” [www.qualitymall.org](http://www.qualitymall.org)

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## MINNESOTA

### Check & Connect

“Check & Connect is a model of sustained intervention for promoting students’ engagement at school and with learning. Demonstrated outcomes include:

- decrease in truancy,
- decrease in dropout rates,
- increase in accrual of credits,
- increase in school completion, and
- impact on literacy.

Check & Connect is data-driven and grounded in research on resiliency and home-school collaboration. Student referral criteria include alterable warning signs of school withdrawal – primarily attendance indices (absences, tardies, or skipping class), in the context of academic performance and emotional or behavioral problems.

Check & Connect is implemented by a person referred to as a monitor or mentor. The person is a cross between a mentor, advocate, and service coordinator whose primary goal is to keep education a salient issue for disengaged students, their teachers and family members. The monitor/mentor works with a caseload of students and families over time (at least two years) and follows their caseload from program to program and school to school.

Check & Connect is structured to maximize personal contact and opportunities to build trusting relationships. Student levels of engagement (such as attendance, grades, suspensions) are “checked” regularly and used to guide the monitors’ efforts to increase and maintain student’s “connection” with school.” <http://ici.umn.edu/checkandconnect/>

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## VIRGINIA (also Transition)

### George Mason Learning Into Future Environments (L.I.F.E.) postsecondary program

“The GMU LIFE Program is an innovative, inclusive postsecondary program for young adults with intellectual disabilities who want to experience college life in a supportive environment.

The GMU LIFE Program has two complementary missions:

- To provide young adults, whose disabilities have traditionally excluded them from higher education, with an inclusive university experience that will further their literacy skills and prepare them for employment and independent living in their communities.
- To provide GMU students who are majoring in disciplines such as education, psychology, assistive technology, social work, etc. with practical experience learning from and working with, individuals with disabilities.



The Program has three Primary Goals:

- Increase Literacy Skills: Reading, Writing, Math, Technology.
- Expand career development, exploration, and employment experiences and options.
- Increase independent living skills and access to community opportunities.

The GMU LIFE Program is designed to be a four to six year program (depending on a student's needs and age). A sample program sequence for a student might be:

Years 1-2: The student attends classes during the day from 9:00 AM to 3:00 PM, Monday through Friday.

Years 3-4: The student may have the option to reside in a residence hall on campus from Sunday through Thursday while attending classes Monday through Friday. (note: the residence hall component is intended to be available beginning the 2005-06 academic year, and will entail additional fees).

Years 5-6: The student will ideally be employed, live with family or as independently as possible in the community, and may attend classes in the evenings.

Students are admitted to the GMU LIFE Program between the ages of 18-22, however students may only remain in the program through the year in which they turn 25.” <http://www.kihd.gmu.edu/gmulife/#mission>

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## **NATIONAL**

### **National Information Center for Children and Youth with Disabilities**

“NICHCY is the national information center that provides information on disabilities and disability-related issues with special focus on children and youth (birth to age 22).

NICHCY has specific information on:

- Specific disabilities
- Special education and related services for children in school
- Individualized education programs
- Parent materials
- Disability organizations
- Professional associations
- Education rights and what the law requires
- Early intervention services for infants and toddlers
- Transition to adult life



The site also offers links to various state resources, NICHCY publications, and information on IDEA. All information is offered in English as well as Spanish.” [www.qualitymall.org](http://www.qualitymall.org)

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## EMPLOYMENT

“As a condition of providing assistance under this title, the Secretary shall require that each recipient of such assistance take affirmative action to employ and advance in employment qualified individuals with disabilities on the same terms and conditions required with respect to the employment of such individuals under the provisions of title V of the Rehabilitation Act of 1973 (29 U.S.C. 791 et seq.)” (DD Act, 2000).

The DD Act defines employment as “activities that result in individuals with developmental disabilities acquiring, retaining, or advancing in paid employment, including supported employment or self employment, in integrated settings in a community” (DD Act, 2000). Further, the Act lists employment at the top of the priorities in achieving inclusion of persons with developmental disabilities.

“The term “supported employment services” means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings, in the case of individuals with developmental disabilities—

- (A) (i) for whom competitive employment has not traditionally occurred; or  
(ii) for whom competitive employment has been interrupted or intermittent as a result of significant disabilities; and
- (B) who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work” (DD Act, 2000).

“A 2003 “Work Trends Report” by the John J. Heldrich Center for Workforce Development at Rutgers University found that ...common reasons that employers don’t hire people with disabilities include the following: discomfort hiring people with disabilities; perceptions that people with disabilities cannot perform the kinds of jobs they have; beliefs that jobseekers with disabilities lack skill and experience; and lack of physical accessibility and fear of the cost of reasonable accommodation.” (National Council on Disabilities, 2004)

“EEOC has identified a number of state employment practices worthy of consideration and even replication. For example:

- The states surveyed include individuals with disabilities as part of their diversity programs and their targeted outreach and recruiting efforts.
- Vermont provides for a “must interview” to anyone with a disability who meets the minimum qualifications for a state job.
- Washington passed legislation creating a supported employment program for individuals who need on-the-job training and long-term support to work successfully.
- Maryland and Vermont have tracked information related to the provision of reasonable accommodations that could be used to assess the effectiveness of their reasonable accommodation procedures.
- In 2004, Florida established the Agency for Persons with Disabilities and Maryland elevated its former Office on Individuals with Disabilities to cabinet- level status. These legislative and executive actions send a clear message “from the top” that people with disabilities are a state priority.” ([http://www.eeoc.gov/initiatives/nfi/int\\_states\\_best\\_practices\\_report.html](http://www.eeoc.gov/initiatives/nfi/int_states_best_practices_report.html))



- Florida has secured a waiver from the Social Security Administration, enabling it to move persons with developmental disabilities into jobs without immediately jeopardizing their eligibility for Medicaid and Social Security Income benefits.
- Vermont has participated in a pilot project to establish “disability program navigators” at four state One Stop Career Centers established under the Workforce Investment Act to help people with disabilities access these services more easily.

A final report detailing the best practices of these four states and a number of others is scheduled for publication in October 2005. That report will likely examine in detail some of these and other practices noted in this interim report.”

[http://www.eeoc.gov/initiatives/nfi/int\\_states\\_best\\_practices\\_report.html](http://www.eeoc.gov/initiatives/nfi/int_states_best_practices_report.html)

## References:

The Developmental Disabilities Assistance & Bill of Rights Act of 2000. Available at: <http://www.acf.hhs.gov/programs/add/DDA.htm>

National Council on Disability. Livable Communities for Adults with Disabilities. December 2, 2004. Washington, D.C.

Some additional promising practices in the states include:

- ☐ Internet-based, self-directed multimedia career assessment system-JobQuest (Colorado)
- ☐ a collaboration to expand employment for hard to serve populations—Project WIN (Colorado)
- ☐ small businesses owned and operated by people with disabilities (Iowa)
- ☐ employment policy group (Iowa)
- ☐ Business Leadership Network (Maryland)
- ☐ internship program for people with disabilities (Maryland)
- ☐ statewide incentive payment system (Maryland)
- ☐ Center on Employment—Institute for Community Inclusion (Massachusetts)
- ☐ personal networks and work in culturally diverse communities—Making Connections Project (Massachusetts)
- ☐ customized employment at one-stop career centers—Customized Works! (Michigan)
- ☐ career networks (Missouri)
- ☐ Association for Persons in Supported Employment (Virginia)



**COLORADO****JobQuest**

“People with intellectual disabilities depend a great deal on work for their quality of life. Working in community-based jobs can make a substantial difference in income, relationships and self-esteem. An important factor in successful employment outcomes is matching individuals with jobs that are of interest to the job seeker. However, existing job interest tools are ineffective for this population due to their text-based nature, the difficulty individuals often have in conceptualizing jobs, and biased responses resulting from the interview format often required to administer them. The proposed Phase II SBIR project will build on the successful results of Phase I to develop Job Quest, an Internet-based, self-directed multimedia career exploration and assessment system for improved job placement of individuals with intellectual and cognitive disabilities. The Job Quest system 1) facilitates self-directed exploration of jobs and job tasks via a media enriched computer environment using digital pictures, audio, and video; 2) enables job developers to identify jobs that match the individual’s job interests through automated searching of the Department of Labor’s O\*NET jobs database, and 3) provides the ability for job developers and employment specialists to customize the content of the system to represent specific jobs which are available in the local community.

In this Phase II project we will further develop and field test the Job Quest system to result in a valuable new tool for job developers and vocational counselors to assess the career interests of individuals with intellectual and other cognitive disabilities. There are over 20 million individuals with cognitive disabilities in the United States. Thus, the size of the target population is quite significant. The system is expected to improve the quality of job matches for many of these individuals by automatically finding jobs that match individual interests. All schools and agencies providing employment training or placement services are potential customers of Job Quest, as well as are all state and private vocational rehabilitation agencies. The personal and societal benefits of improved job matching include increased self esteem and employment stability, higher income, and decreased reliance on public financial support systems.

In summary, the resulting system will meet an important need for innovative new tools to facilitate self-determination in career selection for individuals with intellectual disabilities. In addition, the system will provide a powerful resource to job development specialists to better understand the job interests of the individuals they serve and facilitate communication of career interests by individuals with limited expressive communication skills.” (Daniel Davies, dan@ablelinktech.com, 2005)

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## COLORADO

### WIN Partners

“Colorado WIN Partners is part of JFK Partners/University Center of Excellence in Developmental Disabilities/University of Colorado Health Sciences Center. WIN Partners is currently involved in a collection of national, federal, state and local projects and initiatives. The specific focus/emphasis of WIN Partners is to expand employment and career advancement opportunities for hard to serve populations through innovation and collaboration.

The Project utilized four strategies to result in systems change. These included a: 1) Stakeholders Policy Forum which included policy makers from the various systems to look at recommending policy changes; 2) An Information Clearinghouse where various audiences could receive accurate and updated information, technical assistance and training; 3) Piloting Consumer Navigators within two of Colorado’s Workforce Centers to ensure universal access to all programs and services through these Centers; and, 4) Piloting various Demonstration Projects, e.g., piloting the use of assistive technology in the resource rooms of Workforce Centers to ensure greater accessibility and use by hard to serve populations and looking at creating a Medicaid Buy-In program for Colorado citizens.

The success of Project WIN has also had national impact. Currently, the Consumer Navigator model (now called the Disability Program Navigator) has been replicated in 17 states through grants awarded by the Social Security Administration and U.S. Department of Labor. Colorado has 19 of these positions. Because of our success in implementing the Consumer Navigator model, Colorado WIN Partners has been asked to provide National Technical Assistance, Training for the University of Iowa Law Health Policy and Disability Center, (contractor through SSA and USDOL). They have also asked us to take part in the National Evaluation of the Disability Program Navigators.

Another current project puts the Consumer Navigator on a transition team to assist youth with disabilities who are 14-25 years of age and receiving Social Security Benefits to maximize their economic self-sufficiency. This process demonstration entitled Colorado Youth WINS (Work Incentive Network Supports) was awarded to Colorado WIN Partners/UCHSC from Social Security Administration. Colorado WIN Partners is responsible for designing part of the intervention and creating and implementing the study design and tools to test the interventions...this study is utilizing administrative data from TANF, Food Stamps, the Colorado Department of Labor (including Unemployment Insurance), and Colorado Department of Education.” <http://www.cowinpartners.org/history.asp>

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**IOWA****Uptown Bill's Small Mall**

“Uptown Bill’s Small Mall in Iowa City, Iowa, houses a group of small businesses owned and operated by people with disabilities. In 2001, with support from the Extend the Dream Foundation, Thomas Walz, former Dean of the School of Social Work at the University of Iowa, founded Uptown Bill’s Small Mall—a group of small businesses in downtown Iowa City that are owned and operated by low-income people with disabilities who had never worked before. The businesses include—

- Uptown Bill’s Coffeeshop
- Bill’s Bookmart
- Leslie’s Luxuries (antiques and collectibles)
- Mr. Ed’s SuperGraphics
- Mad Hatter Room (a venue for local music that is alcohol and smoke free, and is also used as a center for Alcoholics Anonymous meetings)
- Gretchen’s Vintage Apparel

Two related offsite businesses are—

- Mick’s Workshop (furniture refinishing and improvement)
- Funk’s Grove Lawn and Garden

The business owners include people with chronic mental illness, cerebral palsy, brain injury, post-traumatic stress disorder, diabetes, and dual diagnosis of mental illness and alcoholism; some use wheelchairs. In addition to the eight owners, Uptown Bill’s Small Mall has dozens of volunteers who maintain property. Many of the volunteers are people with disabilities; others are social work students from the University of Iowa.

In 2002, Walz received the Best Accessible Design Award for the mall from the Governor’s Commission of Persons with Disabilities. The mall, open 365 days a year, is located downtown and can be easily accessed by people living nearby. With its homey quality, the mall has become a neighborhood center that hosts community events and holiday meals.

Using Community Development Block Grants, Iowa City provided a 100 percent rent subsidy to the mall for its first three years and will provide a 50 percent subsidy for another three years. The mall is associated with the University of Iowa School of Social Work, School of Business, School of Nursing, Disabilities Studies Program, and the Department of Psychology...

The businesses in Uptown Bill’s Small Mall are supported by a combination of grants, public funding, volunteers, and their own profits. They provide paid and volunteer opportunities for people with and without disabilities. They also provide an important service to the surrounding community as well as an educational opportunity for university students to work with people with disabilities. The ultimate goal is for the businesses to be self-sufficient and mainstreamed into the larger business community.” (NCD Report)

For more information, see Uptown Bill’s Web site at <http://www.uptownbills.org>.



**IOWA****Employment Policy Group**

“The mission of the employment Policy Group is to promote public policies that encourage a positive return on businesses’ personnel investment and lead to economic self-sufficiency for individuals with disabilities. [They] focus on establishing enduring partnerships among businesses, people with disabilities, educators as well as state and federal policy-makers.

**Activities**

The heart of [their] work is to assist grassroots leaders in their efforts to bring about effective change in workforce-related public policies through:

Policy support to local, state and federal policy makers, based on [their] collective organizational experiences and the lessons learned from careful evaluation.

Collaborative management and strategic planning of applied research and demonstration projects that improve human resource management practices and encourage individuals with disabilities to seek career paths and have access to “high knowledge” and skilled positions.

Training and technical assistance to businesses about workplace support strategies that offers mutually beneficial employment relationships for both employers and their employees with disabilities.

Market research to identify businesses’ human resource management needs and address current policies that impede their ability to recruit, employ and retain people with disabilities.

Community economic development activities to strengthen Iowa’s communities.

Information dissemination through fast facts on current issues, workplace supports and “best practices”.” (www.aucd.org NIRs database)

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**MARYLAND****Business Leadership Network**

“The U.S. Business Leadership Network (USBLN), founded in 1994, is a national, employer-led effort by the U.S. Department of Labor’s ODEP and supported by the U.S. Chamber of Commerce.155 A local chapter, the Eastern Shore Business Leadership Network (ESBLN), won the



2003 USBLN Chapter of the Year Award for best practices in promoting employment of people with disabilities. In its citation, the USBLN said of the Maryland chapter:

The Eastern Shore Business Leadership Network (ESBLN) ... is a proven leader in promoting the employment of persons with disabilities. ... supports and demonstrates the BLN mission: that increasing employment opportunities for people with disabilities is good for business and good for people with disabilities... The organization has recognized the intrinsic value of people with disabilities as employees, consumers, and contributors to the social fabric of our society.

... the ESBLN has expanded to the entire Delmarva Peninsula—including Delaware, nine Maryland counties, and two Virginia counties—and recruited three additional county chambers of commerce (Talbot County Chamber, Cecil County Chamber, and Greater Seaford Chamber). With this expansion, the ESBLN can be promoted throughout its network of 4,000 businesses, individuals, and organizations, significantly increasing the pool of potential employers of people with disabilities.

Specifically, ESBLN's goals are to achieve the following:

- Provide employers with access to prescreened job candidates.
- Decrease the number of people with disabilities who are unemployed or underemployed.
- Provide employers with information about best practices, disabilities, support services, and tax incentives to facilitate employment, training, and retention of people with disabilities.
- Increase general awareness of people with disabilities as valuable employees, entrepreneurs, and consumers in communities.

The ESBLN Web site ([www.esbln.org](http://www.esbln.org)) is the first site in the nation designed to link job-ready candidates with disabilities to employers across the Delmarva Peninsula. The Web site allows employers to search for prescreened job candidates and allows candidates and agencies to search for job openings with employers in specific geographic regions across the Delmarva Peninsula. The Web site, which is sponsored by various corporate members, has been used as a model for BLNs in other locations around the country.

The ESBLN actively works with the Maryland CareerNet One-Stop, which encompasses the Maryland Division of Rehabilitative Services (DORS). According to the USBLN Chapter of the Year Award bestowed on ESBLN, the effectiveness of the partnership between ESBLN and the colocated career center and department of rehabilitation services is demonstrated by an increase in “competitive employment outcomes” (i.e., the number of people with disabilities hired). For example, in 1998, DORS reported successful competitive employment outcomes. In 2002, after working in partnership with the ESBLN and the one-stop career center for a couple of years, the number of successful outcomes had risen to 247, and, after a one-year follow-up, the retention rate of those employees was 85 percent.” (NCD Report, 2004 <http://www.ncd.gov/newsroom/publications/2004/pdf/livablecommunities.pdf> )

For more information visit: [www.esbln.org](http://www.esbln.org)



**MARYLAND****QUEST Internship Program**

“The governor’s QUEST Internship Program for Persons with Disabilities is a successful program that helps people with disabilities gain work experience and become employable in Maryland. The program is administered by the Disability Employment Workgroup, which is a partnership between the Office of Personnel Services and Benefits (OPSB, part of the Department of Budget and Management) and the Department of Disabilities. The Workgroup also includes representatives from other state agencies and the DORS.

The QUEST program started in 2000 with a budget of \$50,000 from the OPSB, which supported six-month contractual positions for approximately 10 interns. But the following year, Maryland’s hiring freeze resulted in changing the program’s structure to a volunteer program with a stipend.” (p. 94)

“Actually, this change was fortuitous. The program is now more flexible and open to a larger pool of candidates, because the requirements for volunteers are designed to be competency-based rather than to emphasize a required amount of relevant work experience to qualify for a position. Internship assignments are varied and have included jobs such as junior accountant, Medicaid program assistant, activity therapist assistant, communication and marketing trainee, and health records clerk. In 2004, 25 positions were filled. Interns receive a \$3,000 stipend for three months of full-time work and \$1,500 for part-time work, paid through the OPSB.” (p. 95)

The QUEST Internship Program benefits interns and agencies alike. Interns with disabilities gain valuable work experience, which helps them become more employable when and if they search for permanent employment, and agencies gain experience in hiring and working with people with disabilities. (NCD Report, 2004)

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**MARYLAND****Employment Initiative Establishes Incentive Payment System**

“On July 1, 2003, the state of Maryland implemented a fiscal incentive program designed to encourage individualized, integrated employment. The system pays an incentive payment to a community supported employment provider for assisting an individual newly entering services to find and maintain a job for six months. In order to be eligible to receive an incentive payment, providers must meet several criteria; among them, the individual must choose their job, be satisfied



with their job, and be paid directly by the employer. Implemented despite budget reductions, this new initiative affirms Maryland's commitment to improving employment outcomes.

Annual rates for day and employment services are calculated based on the service needs of the individual, indirect expenses incurred by providers, and the regional location of services. Rates currently range from \$9,460 to \$17,920 per year, not including an add-on component for one or more units of service beyond the direct and indirect service costs. The incentive payment is 10% of the annual rate for an individual, or between \$946 and \$1,792 for the 2004 fiscal year.

The development of the new system began with the recommendations of the Self-Determination/Employment Task Force. Convened in 2002, the task force highlighted the need to expand employment opportunities by adjusting funding levels, developing an outcome data collection system, and establishing an outcome-based payment system. Funding levels for supported employment were brought into line with funding for other day services in 2002, and the incentive payment system is a first step towards developing an outcome-based approach to supported employment services.” <http://www.communityinclusion.org/publications/word/Maryland10-03.doc>

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## **MASSACHUSETTS**

### **Institute for Community Inclusion**

“ICI has a wide variety of activities focused on enhancing employment opportunities for people with disabilities. Through a variety of services, ICI staff work directly with people with disabilities to help them find and keep employment. ICI staff also provide training and consultation on employment issues to service providers and consumers of services across the country and internationally. ICI also does extensive research on employment issues through numerous research projects.

#### *Individual Placement Project*

The Individual Placement Project provides services to people with disabilities seeking competitive employment in integrated settings.

#### *Supported Work Project*

The Supported Work Project provides services to individuals with mental retardation to facilitate their transition to permanent, unsubsidized employment.

#### *Work Experience Program*

The Work Experience Program at Children's Hospital provides opportunities for individuals with disabilities to experience the world of work. Using work environments throughout the hospital, participants develop personal and vocational skills leading to greater independence. Work



opportunities available include: a variety of general clerical duties, materials handling, food services and messenger work.

#### *Work Tech Solutions*

As a Microsoft-supported initiative, this project uses technology and flexible design strategies (or universal design) to bridge the needs of the business community and the employment needs of people with disabilities. The following services will be offered free of charge during the project's first year of activity: (1) consultation and training to 20 New England businesses; (2) support of 10 Massachusetts job seekers with disabilities to become employed, and (3) an accessible web-based resource that is workplace and employment focused

#### *Training and consultation in employment*

#### *Research in employment*

#### *Center on State Systems and Employment (RRTC)''*

<http://www.communityinclusion.org/programs/employment.html>

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## **MASSACHUSETTS**

### **Making Connections Project: Personal Networks and Work in Culturally Diverse Communities**

“The unemployment rate for people with disabilities in the United States is estimated to be at 70% and has not shown much improvement despite efforts to improve labor force participation. People with disabilities from diverse cultures face even greater challenges, and in most cases are employed at an even lower rate than people with disabilities in general.

To address this issue, the Making Connections Project, in partnership with four community organizations, will identify job search strategies to assist individuals from all cultures in obtaining employment that provides economic self-sufficiency and the opportunity for career advancement. Research from the Institute for Community Inclusion (ICI) suggests that people with disabilities who use personal connections got jobs with better pay and more hours, and the job search took less time.

The purpose of this project is to determine whether a similar benefit could result for people with disabilities from diverse cultures who are introduced to techniques for using personal networks.



The four main goals are to:

- Develop a networking curriculum that accommodates and supports job seekers from diverse cultures
- Provide comprehensive training and post-training support in developing and using personal and professional networks when looking for a job to 48 individuals from diverse cultures.
- Provide technical assistance in personal networking and job development to four community based minority organizations (CBMOs).
- Disseminate curriculum materials and the experiences of individual participants and collaborating organizations using multiple methods including print and Internet based materials.” <http://www.communityinclusion.org/community/connections.html>

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## **MICHIGAN**

### **Customized Works!**

“In Flint, Michigan, Career Alliance, Inc., a One-Stop Career Center serving Genesee and Shiawassee Counties, is pilot-testing “Customized Works!,” a promising new program that may be instrumental in changing the way that One-Stop Centers, rehabilitation organizations, and other providers do business in terms of training and finding employment for people with disabilities.

Michigan Works Career Alliance, Inc., is one of 25 agencies in Michigan that provides employment services to all working-age individuals in the state who need them. While states have a great deal of autonomy in how their One-Stop Career Centers are organized and what services they provide, they are mandated to accommodate all jobseekers, including people with disabilities. Few, if any, however, have gone as far beyond minimum federal guidelines for accessibility and inclusion as Career Alliance, Inc. For example, Career Alliance employs people with disabilities—in fact, about 30 percent of its workforce are people with disabilities. In addition, Career Alliance is pilot-testing a program that approaches expanding employment opportunities for people with disabilities in a new way...

Customized employment starts with the development of an employment plan based on the strengths, needs, and interests of the job candidate with a disability. This is accomplished through an individualized assessment that involves listening to the person with a disability describe his or her experiences, interests, and abilities. Once the candidate’s goals are established, potential employers are identified by looking for a match between the job candidate’s expressed interests and skills and the nature of an employer’s business. A preliminary job proposal is developed and presented to a potential employer, who has voluntarily agreed to negotiate an individualized position that meets the employment needs of the applicant and real business needs of the employer. A personal agent or “job developer” conducts the assessment, develops a plan for the job candidate, assists the candidate throughout the process, and provides follow-up services when appropriate. The idea here is not to try



to fit the jobseeker into a preexisting employment slot, but rather to carve out a job from a traditional job description or negotiate a new position description that matches the applicant's aspirations with the unmet needs of the employer." (NCD Report, 2004)

For more information: [www.careeralliance.org/cworks/](http://www.careeralliance.org/cworks/)

## **MISSOURI**

### **Career Networks**

"The mission of this project is to create career and self-employment opportunities with people with disabilities that are consistent with their gifts, talents, and interests. This project supports the development of personal, community, and statewide networks that are designed to create career and self-employment opportunities for people with disabilities in Missouri, including personal support networks, community Leadership networks, and a statewide career development network to support information sharing and the dissemination of best practices between communities across Missouri.

The Missouri Career Development Initiative is designed to address four primary needs related to career development, career advancement, and self-employment for individuals with the most significant disabilities. These include:

1. Person centered career development is not offered to people with significant disabilities.
2. Individuals in support roles lack the ability to guide and connect job seekers to careers of their choosing.
3. Communities lack a base of Leadership needed to address local barriers to career development.
4. There exists no mechanisms to share best practices related to career development between communities across Missouri...

#### **Outcomes**

Training and technical assistance will be provided to families, job seekers with disabilities, community employment providers, and other community members on the use of person centered career development approaches. This will be accomplished through the facilitation of career planning retreats and the development of a network of community career guides.

A career planning manual and facilitator's guide will be developed to support the career planning retreats. In addition, a web page, an annual best practices in career development monograph, a video titled "Journey to a Career", and a statewide career development symposium will be established to support information dissemination on a statewide basis." [www.aucd.org](http://www.aucd.org) NIRs database

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**VIRGINIA****Association for Persons in Supported Employment**

The Association for Persons in Supported Employment is a rapidly growing organization now numbering over 5000 members. It was formed to improve and expand integrated employment services and outcomes through supported employment for persons experiencing disabilities. APSE members are supported employment professionals, consumers, family members, employers, rehabilitation counselors, advocates, and state and federal agency officials. Membership is open to anyone who wants to be part of a grassroots network committed to ensuring that supported employment continues to grow and improve.

APSE provides a strong voice for supported employment when policy and funding decisions are made.

What members get includes:

- a quarterly newsletter called Advance
- discounts on and free APSE publications
- discounts on sponsored training
- the largest annual conference on supported employment in the world
- an international network of partners
- help finding information and technical assistance
- legislative updates
- action alerts on state and national events
- job search assistance

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**ADDITIONAL RESOURCES:****Job Accommodation Network**

“The Job Accommodation Network (JAN) is a free consulting service of the Office of Disability Employment Policy (ODEP) of the U.S. Department of Labor. JAN’s mission is to facilitate employment and retention of workers with disabilities by providing information on job accommodations and technical assistance to businesses and people with disabilities who are self-employed. Person-to-person technical assistance services include toll-free consultation regarding individual worksite accommodation, individual self-employment accommodation, and individual consultation and referral regarding ADA and other disability legislation. JAN’s annual symposium and outreach activities provide additional



training to private and public organizations. Electronic technical services include JAN's accessible Web site (<http://www.jan.wvu.edu/>), which includes more than 300 disability-specific accommodation publications; JAN's Small-Business and Self-Employment Web site (<http://www.jan.wvu.edu/sbses/>), which contains information about self-employment and small-business ownership opportunities for people with disabilities; and JAN's Searchable Online Accommodation Resource (<http://www.janwvu.edu/soar>), which provides personalized accommodation information. Additional resources include JAN's quarterly newsletter and topical news flash, Consultants' Corner" (NCD Report, 2004).

### **Computer/Electronic Accommodations Program**

"The Computer/Electronic Accommodations Program (CAP) was established in 1990 by the Department of Defense (DoD). In October 2000 CAP became the Federal Government's centrally funded accommodations program through the National Defense Authorization Act. CAP's mission is to provide AT and accommodations at no cost to requesting government agencies to ensure that people with disabilities have equal access to the information environment and opportunities in DoD and throughout the Federal Government.

- The Employment Program assists human resource managers and hiring officials with hiring, recruitment, promotion, and retention of people with disabilities.
- Program Accessibility involves technical assistance, training, and accommodations to meet communication accessibility requirements.
- System Accessibility refers to increasing access to AT, and the accessibility of electronic and information technology." (NCD Report, 2004)

### **Cornell University School of Industrial and Labor Relations Program on Employment and Disability**

"EDI conducts research and provides continuing education and technical assistance on many aspects of disability in the workplace. Since 1968, researchers and practitioners at the Cornell ILR School with expertise in disability have helped companies, labor organizations, government agencies, schools, and communities throughout the United States and abroad to accommodate and integrate individuals with disabilities. The EDI team consults with policy makers, disability advocates, and rehabilitation program professionals.

EDI contributes to developing inclusive workplace systems and communities in a variety of ways. The EDI team engages in research and produces scholarly articles, develops training materials, conducts training sessions domestically and internationally, and offers technical assistance on a wide array of disability-related matters. EDI expertise embraces legal mandates and operational issues, an all-encompassing perspective that enables us to help transform public policy into practice.



EDI provides technical assistance, training, and research in the following topic areas:

- ADA, Accommodation, & Accessible IT
- Disability Statistics Research
- Disability Benefits and Return to Work
- Transition Planning for Youth
- Disability Employment Research
- Workforce Development & Community Inclusion
- International Disability Policy Research” <http://www.ilr.cornell.edu/ped/index.html>

New York State School of Industrial and Labor Relations

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### **The Americans with Disabilities Act**

In the Americans with Disabilities Act, “Title I requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others. For example, it prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment. It restricts questions that can be asked about an applicant’s disability before a job offer is made, and it requires that employers make reasonable accommodations to the known physical or mental limitation of otherwise qualified individuals with disabilities, unless it results in undue hardship. Religious entities with 15 or more employees are covered under title I.”  
[www.usdoj.gov/crt/ada/cguide.htm](http://www.usdoj.gov/crt/ada/cguide.htm)

### **Tax Credits**

“Tax credits are available for small and larger businesses that remove architectural barriers, and for businesses that employ people with disabilities referred from rehabilitation agencies:

- The Disabled Access Tax Credit
- Tax Deduction to Remove Architectural and Transportation Barriers to People with Disabilities and Elderly Individuals
- Targeted Jobs Tax Credit

One of the goals of the NFI is to integrate Americans with disabilities into the workforce. Some key accomplishments include the following:

- Establishing the Access to Telework Fund to allow individuals with disabilities to work from home or other sites and have increased access to computers and other equipment, including adaptive equipment. The Department of Education’s Rehabilitation Services Administration has funded 20 projects under this program.
- Promoting best practices through a partnership between the EEOC and several states (including Maryland, Vermont, Washington, Florida, Utah, and Kansas, ...more states are scheduled for participation in this program) to promote hiring of people with



disabilities in state government jobs. Under this partnership, the EEOC reviews hiring, retention, advancement, and reasonable accommodation practices; provides consultation, outreach, and technical assistance; and will issue a report highlighting best practices that can serve as a model for other states.

- Increasing the SSA's budget to fund several demonstration projects aimed at removing disincentives and providing appropriate employment supports for individuals who want to work.” (National Council on Disability, 2004)



## **FAMILY SUPPORT**

According to the DD Act of 2000, “the term “family support services” means services, supports, and other assistance, provided to families with members who have developmental disabilities, that are designed to-

- (i) strengthen the family’s role as primary caregiver;
- (ii) prevent inappropriate out-of-the-home placement of the members and maintain family unity; and
- (iii) reunite families with members who have been placed out of the home whenever possible” (DD Act, 2000).

Some examples of family support services included in the DD Act (2000) are “respite care, provision of rehabilitation technology and assistive technology, personal assistance services, parent training and counseling, support for families headed by aging caregivers, vehicular and home modifications, and assistance with extraordinary expenses, associated with the needs of individuals with developmental disabilities.”

The State of Connecticut, Department of Mental Retardation conducted a survey of best practices in family support for children with developmental disabilities. Twenty states provided information on what “best practices” constituted in their state ([http://www.dmr.state.ct.us/publications/centralofc/csft\\_appendixc.htm](http://www.dmr.state.ct.us/publications/centralofc/csft_appendixc.htm)). Some of the major areas identified were use of the Equity Fiscal Responsibility Act (TEFRA) under Medicaid to provide extra supports to families of children with home health care needs (Michigan); information sharing from tools such as family satisfaction surveys (most states); community capacity building (North Carolina); and interagency collaboration (Minnesota, Wisconsin, Ohio, New Jersey, Connecticut, Georgia).

Some additional promising practices in family support programs include:

- ☐ increased flexibility in voucher programs (Georgia)
- ☐ family mentor programs (Kentucky)
- ☐ programs that target older family members (New Hampshire)
- ☐ one stops for families of individuals with dual diagnosis (North Dakota)
- ☐ family support specialists / self-determination focus (Oregon)
- ☐ collaborative programs with a cross-disability focus (Pennsylvania)
- ☐ statewide family support networks with local, regional and state councils (Utah)
- ☐ shared parenting (Utah)
- ☐ volunteer training programs in family support (Wyoming)



**GEORGIA (also Funding)****Legacy Express (could be used with persons with DD)**

<http://www.cms.hhs.gov/promisingpractices/gaisf.pdf>

“Legacy Express is a county-based program in northern Georgia aimed at improving the quality of services provided to older adults and their caregivers. Legacy Express provides vouchers to caregivers, which may be spent on service options ranging from respite care and medications to haircuts and lawn care. The objective is to give caregivers the authority and flexibility to select those service options that work best for them. Originally targeted at persons with Alzheimer’s Disease, the program has gradually been expanded to serve all eligible older adults and their caregivers” (p. 1)

“Older adults and their caregivers can benefit from a wide variety of services. For example, a family may want adult day care one day and help with their lawn the next. Yet many programs limit the scope of available services. As a result, caregivers are often unable to obtain the assistance they need for those in their charge. The State of Georgia and Legacy Link, an Area Agency on Aging in northern Georgia, offer vouchers to caregivers that they can spend on a wide range of services... Under Legacy Express, caregivers receive one or two book(s) of \$10, \$20, and \$50 vouchers (total value: \$1,000 per year), which can be used to purchase services from approved providers.”

“The program has been expanded considerably since its inception, both in the population it serves and the services it offers. In 2001, the state used money provided under AoA’s National Family Caregiver Support Program to expand eligibility for the program to anyone caring for an older adult family member—such as older Americans suffering from chronic illness or stroke. In 2002, the Area Agency on Aging implemented a new voucher program in four additional counties. Under the new program, vouchers are provided directly to caregivers, and caregivers then have the option of hiring relatives and friends for their caregiving services. The program is currently available in eight counties.”

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## Kentucky

### Kentucky Family Support Project

“Kentucky Spin proposes to expand family support activities statewide to include families and guardians of persons with disabilities of all ages, with a special focus on previously unserved and/or minority families. Through a coordinated system of all relevant state and local agencies, including Kentucky’s school-based Family Resource and Youth Services Center, Special Education Parent Resource Centers, and family and consumer advocacy groups, this project will provide training to a minimum of 1,000 families on family supports, advocacy, and systems change. Participating families will be matched with a family who has successfully dealt with similar life issues (e.g., inclusive education, transition, supported or independent living, employment, etc.) or will be linked to other established support groups. Supports will be available on a regional basis, with more local, family-friendly centers for parent and families.” (<http://www.acf.hhs.gov/programs/add/pnsfs.htm>)

Kentucky Spin

<http://www.kyspin.com/index.cfm>

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## NEW HAMPSHIRE

### Family Support Partnership Project

“Goal: To create a statewide, family-centered, culturally competent, community based infrastructure to support older families who are caring for their sons and daughters with developmental disabilities who are living at home.

The above goal will be achieved by working with each region individually, meeting the needs of the older families in each region. As each region has its own goals on how to support families, those of the project will complement those of the region.

In each region, the Project Team with the staff of the region to develop, enhance or expand supports and services that will meet the needs of older families. The following project objectives will be incorporated in each region:

- Enhancing the current family support systems to meet the needs of older families. This will be done by offering leadership training; developing and determining how to financially support services that are family driven, meeting the needs of the older parents caring for their adult children; working with family support councils; and improving the management of data.



- Expanding the Parent-to-Parent networks to meet the needs of older families. Mentors will be used to support older parents.
- Individualized family supports will be developed. When available, system dollars will be allocated to meet the particular needs of families.
- Working relationships will be enhanced between the groups that support families headed by older caregivers.
- The capacity of existing community groups and volunteer organizations will be enhanced to include individuals with developmental disabilities and their families in their activities and outreach efforts.
- Information about trusts, guardianship, wills, personal futures planning, etc. will be developed and disseminated to the regions and families.

Project Partners are: Community Support Network, Inc. (CSNI), The Institute on Disability, The Division of Developmental Services, and the Franklin Pierce Law Center” [http://csni.org/fsp\\_intro.htm](http://csni.org/fsp_intro.htm)

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## **NORTH DAKOTA**

### **One Stop for Families of Younger Persons with Dual Diagnosis**

“This project supports a statewide partnership among the ND Dept. of Human Services through 8 regional Human Service centers and various state and private family support agencies and the North Dakota Center for Persons with Disabilities (NDCPD) at MSU. The project will develop a statewide implementation plan that will enable existing Human Service Centers to act as one-stop service centers for ND families whose children have concomitant intellectual and emotional/behavioral disorders” <http://165.234.216.166/proj/current/onestop.htm>

“The North Dakota OneStop Project (ND OneStop) will evaluate the efficacy of using the current regional human services centers as a one-stop system for families of individuals with dual MR/DD and mental health conditions. [They] will especially focus on those individuals who are 21 years old or younger. ND OneStop will produce a written plan outlining a viable process for serving 50 or more families with these co-occurring conditions” (Haarstad, p. 2)

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**OREGON (also Self-Determination)**

“The family In-Home support Project’s main focus is to promote the fact that it is in the family-centered planning and writing of an individualized and creative annual plan that will develop the supports and resources that will truly make a difference in the quality of life for families and children with developmental disabilities.

The family In-Home support Project is providing the training and technical assistance across the State of Oregon to: ensure a smooth transition from Self-Directed support (SDS) program services to county family support (FS) services; to build competencies for the FS Specialist in both the technical aspects of service delivery as well as delivering services using family-centered planning and the values and philosophies of Self-Determination; to assist each county to incorporate FS training into their case management orientation; and to provide mentoring and T & TA to the consumer-directed policy groups that will result in their having significant influence in the development and oversight of these FS Programs.

The Training and TA will be delivered mostly through regional training where peer networking will be developed and encouraged as well as two specialized trainings for: 1) issues related to domestic employees and/or contractors working in the family homes and 2) discussing the roles and responsibilities of the consumer-directed policy groups with both the DD Program managers and the policy group chairpersons. We will be holding a statewide family support event in partnership with the Arc of Oregon, Lifespan respite and Oregon Council on Developmental Disability where we will be presenting best practices, providing information about accessing existing resources with families and professionals, and strategies for building relationships that would result in the further creation of quality community resources.

Material development and dissemination is a big component of this project. Manuals for family support Specialists have been developed which present the philosophy of Self-Determination and family support as well as detail the technical requirements of writing plans and expending both State general funds and Medicaid funds. A Guide for Consumer-Directed Policy Groups will be available to use as teaching tools for the recruitment, orientation and mentoring of new members, using strategic planning and quality assurance practices, understanding successful governance group structures and how communication can influence the group culture as well as conflict management.”  
[http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=747&keywords=%22family%20support%22](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=747&keywords=%22family%20support%22)

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Center on Self Determination

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## PENNSYLVANIA

### PA Family Support Implementation and Coordination Project

“With collaborative efforts of state agencies and representatives of families of children with developmental disabilities, the goals of this project are to expand the current system of supports and create a comprehensive program for all citizens with DD, to include decision-making roles of individuals and family members, strengthen community capacity, and improve the quality of life for these individuals. The project will work to use state funds to provide respite services to children with physical disabilities along with existing state-funded family support programs; and with Council grantees and DD Act partners to create an array of coordinated and expanded supports that are cross disability, comprehensive, family directed, culturally competent, community based, coordinated across disability program offices, rooted in the use of generic resources and informal supports, and based on the concepts of learning and implementation of a self-determination model” <http://www.acf.hhs.gov/programs/add/pnsfs.htm>

“The PA Family Support Implementation and Coordination Project which is a collaborative effort of The Developmental Disabilities Council, Temple’s University Center on Developmental Disabilities and UCP of PA has received additional funding from the Federal Administration on Developmental Disabilities. This enables the efforts of advocates for service to children and families to continue. Activities of the project include educating policy-makers about the importance and effectiveness of family-driven services, closing unfair gaps in our service system, and distributing information about available services. The Project will focus on a specific aspect of family support where little information has been gathered - families in which the parent has a disability. The Project will conduct focus groups to learn about the experience of this group, and then conduct a demonstration program to address specific issues” [http://www.ucp.org/ucp\\_localdoc.cfm/130/9356/9356/9356-9356/5248](http://www.ucp.org/ucp_localdoc.cfm/130/9356/9356/9356-9356/5248)

## UTAH

### The Family Council

“Families of people with disabilities in Utah often did not know how to seek publicly and privately funded services. Most supports available to families were parent training centers and support groups that catered to individuals with particular disabilities. Several families in Utah formed the Family Council, a nonprofit organization that enables all families of people with disabilities to support one another, share ideas, and learn about available services. Using funds from a Self-Determination Grant from the Robert Wood Johnson Foundation, the State of Utah provided support to increase availability and awareness of the Family Council’s services throughout the state.”

“The Family Council in Utah has a total of 35 local, regional, and state level Family Councils. The Regional Councils represent the four regions of the state and consist of selected Local Council officers. The State Council consists of representatives from the four Regional Councils. The Chair and the Vice Chair of the State Council meet with the Director of the DSPD on a monthly basis to provide feedback regarding issues and policies from a family members’ perspective. At each level, family members of individuals with disabilities completely manage the Councils” <http://www.cms.hhs.gov/promisingpractices/utfds.pdf>



## Shared Parenting

“The state of Utah developed a professional parent and shared parenting program that serves many children with challenging needs. This program model has been replicated in Oregon and Washington. Each professional parent is required to work with support staff assigned to their home in carrying out activities with the child. Support staff provide respite to the professional parents. When the child is with his or her natural parents, support staff provides identical services to them. This assures continuity for the child and also recognizes the need for support by both sets of parents” ([http://www.dmr.state.ct.us/publications/centralofc/csft\\_appendixc.htm](http://www.dmr.state.ct.us/publications/centralofc/csft_appendixc.htm)).

“Professional Parent Supports are available for clients under 22 years old, who prefer living in a private residence with a family or caregiver (non-related; parent or guardian), who may need out-of-home placement for either a short or an extended period of time. Professional Parent Supports are established to give children and youth with disabilities an alternative to institutional or community living settings, such as group homes and apartments. This program allows a child or youth to be placed with a family or caregiver who has received specific training regarding disabilities.”

“Professional Parents serve children with disabilities under 22 years of age in private residences where they receive therapeutic residential habilitation services. Professional Parents cannot have custody or guardianship of the child. When children with a disability cannot remain with their own families for whatever reason, the out of home placement in a Professional Parent home is a preferred alternative. Professional Parents assist the young people in developing skills and provide support in the activities of daily living (bathing, eating, dressing, personal hygiene)” ([http://www.dspd.utah.gov/overview\\_professionalparent.htm](http://www.dspd.utah.gov/overview_professionalparent.htm)).

## WYOMING

### Wind Family Support Network (volunteer trainers)

“Given the distances between Wyoming towns and its small population, people with disabilities and families of children with disabilities find it very hard to access support from other families of persons with disabilities or to know where and how to access services. While agencies will sometimes provide trainings and workshops about available services for families and people with disabilities, there needs to be a local contact to follow up with these families and individuals or training just becomes a one-time affair that has no lasting affect in the community. Another factor is that many times people with disabilities or families of children with disabilities do not attend meetings. This last point is especially true for workshops or trainings on disability issues on the Wind River Reservation. There are few phones and few working cars for the families living on the reservation; personal contact is much more effective.”

“The WIND family support Network (WFSN) model provides the structure and direction for volunteer “pathfinders” to identify and support families with both young and adult children with disabilities. The (WFSN) is a statewide network of volunteer parents, family members and/or guardians of children with disabilities of all ages. The WFSN works to inform, educate and empower local families as they participate in the education and community inclusion for their children. The



(WFSN) utilizes grant monies to provide quarterly trainings for the volunteers with the expectation that the volunteers will return to their communities and share the information they have received.

The goals of the WIND project are to:

- ☐ Provide immediate contact with families of children with disabilities of all ages throughout the State of Wyoming.
- ☐ Empower families of children with disabilities of all ages to be able to advocate for their children in any meeting in which they are called upon to participate by providing four statewide trainings.
- ☐ Expand the growth of volunteers within the WFSN with an emphasis on serving unserved and underserved populations.
- ☐ Maintain a collaborative working and training relationship with developmental preschools, Head Start programs, school districts and other agencies that work with people with disabilities throughout the life span.
- ☐ Conduct statewide forums to solicit input from families of children with disabilities of all ages regarding family support programs, policies and plans for such families.
- ☐ Evaluate the effectiveness of the WFSN model and adapt and modify approach as necessary.
- ☐ ...Whenever possible, the WFSN reimburses the extra costs involved in being an advocate in Wyoming, such as traveling many miles and spending a night away from home to assist families with meetings with professionals”  
([http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=1042&keywords=wfsn](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=1042&keywords=wfsn))



## FUNDING

The self-determination movement has resulted in changes in the way services and supports are funded (Bradley, 2004). Some of these changes include changes in rate structures, changes in the role of case managers and service brokers, individualized budgets, microboards, portable funding strategies, and changes in the demands on management information systems.

A **microboard** is a “small board of either 5, 7 or 9 individuals that form a board around the person with a disability who needs supports” (<http://www.self-determination.com/publications/microboard.html>) They are sometimes referred to as a Self-Directed Support Corporation or SDSC.

“The SDSC is responsible for arranging supports for the individual with the disability. Under the principles of self-determination and tools used to implement self-determination we are looking at individual budgets, support brokerage and fiscal intermediaries. SDSC’s process incorporates the best practices of this approach.

The SDSC becomes the support broker. You use Home and Community Based Waiver funding to provide support services. Since you are a provider for one person, this means a true individual budget. Fiscal Intermediary can be your local bank.

What does this mean to people with disabilities? What it means is true control and freedom to the person with the disability. Friends and family who know the individual are encouraged to become a member of the board. Yet, you are required to have more non-family members preventing the family from controlling the individual with the disability. The board does the directing of supports on a volunteer basis, so there is no conflict of interest for them.

What does this mean for the government? What it means for the government is a cost effective, person centered approach to supporting an individual with a disability. It cuts the administrative cost at the same time it presents an opportunity for the person with the disability to control their budget and present true accountability to the state and federal governments. The SDSC follows all the regulations as any other provider of services. This includes becoming a Medicaid provider approved by the state and conducting audits and reviews by the state agencies” (Center for Self-Determination, <http://www.self-determination.com/publications/microboard.html>)

Individual budgeting practices are available in most states though the extent of individual budgeting alternatives varied tremendously between the states (Moseley, 2004, <http://ici.umn.edu/products/impact/171/171.pdf>). Moseley identified three methods for assessing individual need when developing individualized budgets.

1. Developmental – determines the individual’s needs through a person-centered planning process.
2. Statistical – uses a standardized formula for determining need and, sometimes, funding/allocation levels.
3. Combination of the developmental and statistical methods.

Some promising practices in the states include microboards or Self-Directed Support Corporations (Arizona, Colorado, Maryland, Missouri, New Hampshire, Oklahoma, Oregon, Pennsylvania, Tennessee, Utah, and Virginia); individualized budgets (Wisconsin); fiscal intermediaries (Arizona, Indiana, North Carolina, Utah, Wisconsin) and Money Follows the Person initiatives (i.e., Texas). Often states use a combination of these practices to deliver services.



## MAINE

“The Maine Department of Behavioral and Developmental Services is adopting a standardized assessment and budgeting process for mental retardation waiver services that results in consistent, predictable, and truly portable budgets. The State is directing resources toward more person-centered, consumer-driven services offered in the most integrated and appropriate setting and identifying cross-system performance measures that enable Maine to comprehensively and coherently assess its success at achieving a balance of services across systems. Maine is piloting an individual budget tool and assessing its impact on consumer satisfaction, providers, budget neutrality, staffing requirements, and Medicaid management information systems.” [http://www.hcbs.org/files/47/2306/MFP\\_CMS\\_letter.pdf](http://www.hcbs.org/files/47/2306/MFP_CMS_letter.pdf)

## NEW HAMPSHIRE (also Transition)

### Enhancing Transition through microboards

“This four-year demonstration project is working to establishing 36 pilot microboards for transitioning youth, twelve in each of three regions of New Hampshire. This effort includes working with schools and adult service organizations to insure that funding resources in the three regions can be made available to implement plans developed by the microboards. The project will evaluate the transition process and outcomes for participants with microboards and a comparison group of 36 individuals involved in a more traditional transition process. Anticipated outcomes for participants include increases in satisfaction with life goals and progress towards goals, completion of high school, post-secondary education, employment, and increased community participation. Participants in the project are young adults in the three demonstration communities who are 19 or 20 years old at project entry who are enrolled in public high school and eligible for special education. Referrals are obtained from participating high schools in the three selected communities.

Each participant in the Microboard demonstration receives the following services:

- Assistance in identifying a small group of adults who agree to meet periodically as a microboard, and help the participant sort out post-high-school goals and plans, make decisions, and pursue accessing the goods and services needed to make the plan a reality. Each microboard has access to a small amount of project funds to contract with an independent facilitator to facilitate periodic meetings and ensure that plans are developed and implemented.
- Assistance making arrangements with funding sources to individualize service funds available to the participant and make funds available to a student “Transition Account” to pay for supports and services as decided and directed by the microboard, to the maximum extent allowable by each funding source’s regulations. microboards have the option to incorporate individually and receive funds, or to utilize a fiscal intermediary organization, and other options may be developed over time.
- Assistance to microboards in negotiating service agreements and overseeing the quality of services purchased, and in utilizing a broad base of financial resources, including not only traditional funding sources but also nontraditional funding sources (e.g. PASS Plans), “generic” sources of assistance



(e.g. college financial aid, federal Workforce Investment training funds), and resources contributed by the participant and his or her family, including natural supports and in-kind contributions.

- Consultation on benefits planning and work incentives related to insuring that needed medical insurance is maintained while transitioning students are beginning to earn income.
- Support for training and ongoing mentoring for microboard facilitators, to ensure the availability of high quality independent facilitators for personal futures planning.

Participants in the microboard demonstration and in the comparison group complete an in-person interview every 6 months about their educational status (enrollment, attendance, and progress), community participation status and career status (career plan, work history, current employment). In addition, satisfaction with the planning process and on the strength of the “working alliance” between the participant and his or her planning team in both groups will be evaluated.” [http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=4052&keywords=microboards](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=4052&keywords=microboards)

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Title microboards handbook

Date of Publication Author(s) Cloutier, Heidi, Hagner, David

## **NORTH CAROLINA**

### **The Arc as Fiscal Intermediary**

<http://ici.umn.edu/products/impact/171/171.pdf>

“In August 2001, The Arc launched the first employer of record service in the state. This service provides a mechanism for people with disabilities and families to take more responsibility in hiring and managing their own support staff, while The Arc ensures that all the necessary rules and regulations are met. To begin the process, each person or family receives information about the total funds available to them to support the services they need. Through person/family centered planning they ultimately determine which services will meet their specific needs within the framework of state defined service options. They begin building a personal budget by projecting dollars to be earned through the provision of those services, as well as the associated costs, such as paying employees and purchasing administrative services from The Arc. As they add up costs and make adjustments to their proposed budget they may have funds available to purchase “extra” supports and services outside what the system typically offers, such as private counseling. After services are rendered, billed for, and payment received by The Arc, bills for those “extra” supports and services can be handed to The Arc for payment. Functioning as a fiscal intermediary, The Arc pays the bill and subtracts the payment from the total of the individual’s/family’s funds. This provides some initial flexibility in using the funds available for support services to meet individuals’ or families’ needs and requests” (p. 12).



## TENNESSEE

Tennessee Microboard Association provides technical assistance and training to people and families who want to create and use microboards for people with developmental disabilities. TMA has incorporated, elected their Board of Directors, provided PATH training across Tennessee, completed 30 PATHs across the State, helped 10 microboards to form and incorporate, and helped to file applications with DMRS to become service providers. Three microboards are approved providers and two are operating as providers (i.e. receiving funding).

Tennessee <http://www.state.tn.us/cdd/families.html>

## TEXAS

### Money Follows the Person

“In 2001, the Texas Department of Human Services implemented a law that provides for Medicaid funding to follow an individual when transitioning from a nursing facility to the community. The law specified that as individuals “relocate from nursing facilities to community care, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services.” The Texas law represents a good example of an initiative that can be undertaken relatively quickly, without requiring major restructuring of the long-term care system.

The Texas Department of Human Services has assisted more than 700 individuals to transition to community living since the effective date of the law in September 2001. The Department developed procedures for informing nursing facility residents, responding to requests for assessments and care planning, and then assisting with the transitions.” <http://www.hcbs.org/files/47/2312/smd81302.pdf> (p. 2)

[http://www.dads.state.tx.us/business/pi/MFP\\_trainingoverview504.pdf](http://www.dads.state.tx.us/business/pi/MFP_trainingoverview504.pdf)

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## UTAH

### Acumen Fiscal Intermediaries

“The concept behind the development of Acumen Fiscal Agent is straightforward. Providing people with the financial supports to be the employer of record eliminates “employer” headaches and minimizes their legal exposure to funding entities and ensures compliance with employer law. The result is people having more control over the kinds of supports they choose, a decrease in the amount of money associated with the administration of those funds, less paperwork and compliance headaches, and more responsibility and accountability for the supports they receive. However, the most appealing concept is the development of a new kind of work force (i.e., people are able to hire



friends, neighbors, relatives, etc.) resulting in the expansion of one's circle of support as well as the quality and length of those supports.

Acumen Fiscal Agent began its journey for system change in 1996 in the State of Utah. A quote by James William best describes this continuous journey: "A new idea is first condemned as ridiculous, and then dismissed as trivial, until finally it becomes what everybody knows." This has truly been the case with Acumen. Today, Acumen consultants are reaching out to populations across the nation with a commitment to help people to live the best lives possible. Acumen is creating positive changes by helping systems to "un-bundle" services and supports while still ensuring accountability.

Acumen's Fiscal Intermediary Model allows the person or family needing supports to:

- Be the employer of record. They can hire, fire, schedule and train their own employees
- Contract with consultants and contractors of their choice for support
- Purchase supports like Chore Services, Personal Assistance, Attendant Care, Respite, and liability insurance as needed
- Buy equipment and other essential items directly from the vendor of their choice

In addition, Acumen's Fiscal Intermediary Model:

- Trains the person or representative on how to be an employer
- Supplies all the required forms for the person to hire employees or contract for services and supports
- Facilitates people "pooling" their supports, thereby helping their money to go further
- Processes payroll and related contracted services bills
- Bills funding sources on behalf of the person, as supports are delivered
- Provides continual account balance information to the person and the funding source(s) by providing declining balances to assure the support allocation is not over spent
- Assists people with the state and federal "paper requirements" of their support plans
- Represents the person with the IRS, State and Department of Labor for payroll reporting purposes
- Provides ongoing communication and tips through customer service representatives, memos and newsletters
- Offers medical and dental insurance to the consumers employees" <http://www.qualitymall.org/products/prod5.asp?prodid=268>

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## WISCONSIN (also Self- Determination)

### Self-Directed Services/Individualized Budgets

“Dane County is moving towards a model of service called Self-Directed Support. It is also known as self-determination. In this service model, the person receiving services and those who know the person well, such as the family, guardian, and friends, decide how best to use the money allocated for the consumer.

The new structure allows the county to offer self-directed supports to all adults who are entering the service system, receiving additional service or requesting self-directed services.

Key elements of self-directed support are:

Consumer control over an individual budget.

- The county sets an annual budget for the individual. The budget is based on the cost of past supports and current circumstances.
- Individuals, and those who know them well, plan services within the amount of the budget. They have the opportunity to determine what to buy, who to buy it from and when to buy it.
- If a person comes in under budget, their budget is not reduced the next year.
- Reserve funds are available to allow for changing needs.

Use of a support broker.

- The support broker is responsible for assisting with the development and implementation of the person’s plan.
- The consumer chooses the support broker.
- The support broker’s responsibilities are:
  - Helping identify the individual’s goals.
  - Developing individualized support plans. Plans include how the individual wants to live, and also those elements of an individual’s life that are non-negotiable (those things that cannot be compromised).
  - Identifying informal and generic supports as well as traditional human service agencies.
  - Helping to choose supports that fulfill the goals of the individualized plan.
  - Using the allocated budget creatively.
  - Negotiating rates and contracting for services with the chosen providers.
  - Monitoring the supports for quality on an ongoing basis.

Assistance with managing budgets.

- Consumer control of funds does not require that the consumer have the skills or commitment to carry out money management.
- The broker can help arrange for a variety of methods of payment. Some, such as contracting, will look similar to today’s system. Others, such as use of employment services to directly hire staff, will be quite different.
- A fiscal management agency makes sure that the money is spent as written in the individualized plan.



Ensuring quality, health and safety.

- The support broker is responsible for making sure that plans protect consumer health and safety.
- The current protective systems for the prevention of abuse and neglect will remain in place.
- Additional evaluation tools will be used to measure consumer satisfaction, level of consumer control, and achievement of consumer goals.” <http://www.co.dane.wi.us/humanservices/acs/selfdirect.htm>

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**Supplemental Readings:**

<http://ici.umn.edu/products/impact/171/171.pdf>

[http://www.hcbs.org/files/51/2545/SystemsChangeYear2Report\\_final\\_101504.doc](http://www.hcbs.org/files/51/2545/SystemsChangeYear2Report_final_101504.doc)



## **HEALTH-RELATED ACTIVITIES**

According to the DD Act of 2000, the term “health-related activities” means “advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities, in their communities.”

Some promising practices in health related activities for persons with DD include:

- ☐ assessing state capacity in health care delivery system for Medicaid beneficiaries, particularly those with special health care needs (Arizona, California, Kentucky, Massachusetts, Missouri, Oregon)
- ☐ family caregiver education (Colorado, New Jersey, Oregon)
- ☐ promoting healthy lifestyles in health promotion programs (Illinois, Montana, North Carolina, Oregon, Pennsylvania)
- ☐ oral health training for non-dental health care professionals (Massachusetts)
- ☐ health promotion (Montana)
- ☐ statewide Telehealth Network (Nebraska)
- ☐ effectiveness of personal support technology for improving the oral health (New York)
- ☐ women’s health (North Carolina)
- ☐ reduction of secondary conditions (Oregon)
- ☐ Project Good (Pennsylvania)
- ☐ rural education (West Virginia)
- ☐ educating health care professionals program (National Down Syndrome Society, West Virginia)

## **ARIZONA, CALIFORNIA, KENTUCKY, MASSACHUSETTS, MISSOURI, OREGON**

### **Improving States’ Ability to Assess the Adequacy of Health Plan Networks**

“The primary purpose of this project is to enable regulators and public purchasers to ensure that health plans have the provider capacity necessary to care for their enrolled population. Information on better ways to assess provider capacity will also help health plans and private purchasers. The grantee will prepare a publishable final report describing approaches in practice or under development to assess network adequacy.” [http://www.chcs.org/grants\\_info3963/grants\\_info\\_show.htm?doc\\_id=206552](http://www.chcs.org/grants_info3963/grants_info_show.htm?doc_id=206552)



Publications:

***Ensuring Special Needs Populations' Access to Providers in Managed Care Networks*** [http://www.chcs.org/publications3960/publications\\_show.htm?doc\\_id=211929](http://www.chcs.org/publications3960/publications_show.htm?doc_id=211929)

***Ensuring Special Needs Populations' Access to Providers in Managed Care Networks***- “a toolkit aims to assist states in defining their network adequacy system, and guide them through five steps: 1. Determine how high a priority network adequacy should be for the state. 2. Assemble and review information on the special needs populations to shape priorities. 3. Identify the state’s system for network adequacy. 4. Assess the state’s system and consider what other states are doing. 5. Define realistic next steps.”

“This toolkit should be useful in assessing and ensuring network adequacy for special populations, such as those with behavioral health needs and persons with disabilities, and also the general Medicaid population, although standards and reporting may differ between these groups.” [http://www.chcs.org/publications3960/publications\\_show.htm?doc\\_id=211929](http://www.chcs.org/publications3960/publications_show.htm?doc_id=211929)

## **COLORADO, NEW JERSEY, AND OREGON**

### **National Foundation of Dentistry for the Handicapped: *BRIDGE* (Campaign of Concern/Outreach Education)**

<http://www.nfdh.org>

“People with developmental disabilities (DD) often cannot care for their oral health and have difficulties getting treatment. Their problems can be exacerbated because caregivers have difficulty helping clients with their dental hygiene.

BRIDGE staff provides in-service training to nurses, teachers, case managers, residential staff, and parents of adult DD children to help improve oral hygiene and to follow up with routine dental care. In some cases, BRIDGE staff may act as case managers for DD patients by assisting those who are not receiving care and coordinating treatment with social support services, dentists, or through DDS or Dental HouseCalls.” <http://www.nfdh.org/Campaign.html>

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## ILLINOIS

### **Healthy Communities for Adults with Intellectual and Developmental Disabilities: Evaluating the Efficacy of Two Train-the-Trainer Approaches**

Goals:

- “Evaluate the efficacy of two train-the-trainer approaches (web-based vs traditional) for promoting and maintaining healthy behaviors among adults with I/DD
- Identify strategies for agency staff to implement a health promotion program for adults with I/DD
- Identify ways to increase healthy behaviors among adults with I/DD” <http://www.uic.edu/orgs/rrtcamr/research1.html>

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### **Exercise Adherence among Adults with Mental Retardation**

“This project is the first to examine the effectiveness of a health promotion program in improving health and well-being of adults with mental retardation. The purpose of the study is to determine if a 12-week exercise and training program can help adults with mental retardation by improving their health and happiness over a two-year period. The study will also determine if a caregiver education program can increase their exercise participation over a two year period.”

<http://www.uic.edu/orgs/rrtcamr/ExerciseAdherenceFinalReport.pdf>

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## **MASSACHUSETTS (also Education/Early Intervention)**

### **Early Intervention and Education In Oral Health (EIEIOH)**

“The oral health Training project has developed a training program to assist non-dental health professionals, such as pediatricians and nurse practitioners, in assessing pre-school children for early childhood caries (ECC) and to help them provide appropriate guidance to caregivers. The program’s main teaching method is the use of clinical slides to show common oral health pathology as well as healthy oral cavities. A previous EIEIOH study indicates that emphasis on clinical photographs is a



highly effective educational tool to improve clinical recognition of early signs of caries and most aspects of related anticipatory guidance and provision of essential preventive care measures. The education of non-dental health care professionals for this purpose is especially important in populations with low access to dental care or who may otherwise be at high-risk. The addition of a post-test for Continuing Education credit is possible. This would require collaboration with local and state educational centers and health professional agencies.” [http://www.uclid.org:8080/uclid/ie\\_oral\\_health.html](http://www.uclid.org:8080/uclid/ie_oral_health.html)

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## **MONTANA**

### **The Health Club: Health Promotion for People with Developmental Disabilities**

People with developmental disabilities experience a high rate of secondary conditions. Also, supported living programs experience a high rate of turnover of personal assistance staff, which is a key risk factor for experiencing secondary conditions. The goal of this project is to develop, demonstrate and evaluate the effectiveness of a new intervention system. The Health Club is designed to prevent secondary conditions and maintain and improve the health of adults with developmental disabilities living in supported living arrangements. This project stems from a cost-effective program, Living Well with a Disability, which has been implemented in 16 states and 40 Centers for Independent Living. This is a model program for organizing in-home services and supports to prevent and manage secondary conditions. The project will organize the programmatic components of The Health Club model of health education and health promotion activities, and document procedures for its implementation, and then pilot test and refine The Health Club program in one support living setting. The behavioral methods that will be utilized have been shown to be highly effective in establishing and maintaining functional repertoires and in reducing undesirable and self-injurious behavior for this population.

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### **Montana Disability Health Program: Living Well Under the Big Sky**

“The GOAL of The Montana Disability and Health Program is to assess, monitor, improve and maintain the health of Montanans with disabilities through a strategic program that reduces secondary conditions by enhancing individuals’ capacity to manage their own health and by developing supportive community environments.



**Objectives Include:**

- Establish the organizational structure and location within the collaborating agencies.
- Establish a mentoring relationship with an existing Level I state-based program to learn what works, what doesn't, and how to overcome barriers to managing and operating an effective health and disability program.
- Organize an Advisory Board and processes to guide the program.
- Organize a broad Disability and health Network of community partners representing relevant constituent groups to focus on improving the health of people with disabilities in Montana.
- Develop a long-range strategic plan for operating and evaluating the Montana Disability and health Program.
- Organize and implement an evidence-based approach to assessing and monitoring the health of Montanans with disabilities.
- Assemble and review existing data reflecting the health of Montanans with disabilities.
- Collect new data where useful.
- Develop a State Disability and health Plan and/or include such objectives in other state health plans.
- Organize a program to infuse disability health and wellness goals into the plans, policies, programs and procedures of state agencies and community service providers.
- Disseminate health promotion information through diverse and innovative marketing.
- Plan, implement, and evaluate health promotion interventions that prevent and manage secondary conditions and improve the health of Montanans with disabilities.
- Develop a plan to transition the leadership of the Montana Disability and Health Program to Montana DPHHS." <http://mtdh.ruralinstitute.umt.edu/OurPlan.htm>

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**NEBRASKA****Statewide Telehealth Network**

“Recently, Nebraska Governor Mike Johanns announced that Nebraska now has the ability to connect State health officials with more than 40 hospitals throughout Nebraska for interactive video-conferencing. The ability is critical in the event of an emergency, as well as to provide Nebraskans access to health specialists without leaving their hometowns.

Eventually, the Nebraska Statewide Telehealth Network will connect to every Nebraska hospital, local public health department, State and regional public health lab, and key State agency. A key part of the network will allow genetic specialists at the University of Nebraska Medical Center's (UNMC's) Munroe-Meyer Institute to connect with patients at Regional West Medical Center in Scottsbluff and Good Samaritan Hospital in Kearney through video-conferencing technology. The telehealth system is the first in Nebraska for children with special health care needs.



Dr. Schaefer's team sees about 2,000 Nebraska patients a year on the road. The telehealth network could enable specialists to conduct 4,000 more visits a year, increasing the number of people served and improving the quality of care for existing patients whose doctors may have seen them less frequently in the past because of the distance." <http://www.atsp.org/government/programs.asp?contentID=1707&FullStory=>

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## NEW YORK

### **Innovation in Health Promotion and Communication: A Research Project to Demonstrate the Effectiveness of Personal Support Technology for Improving the Oral Health of Adults with Mental Retardation**

"There is a long-standing problem of major health disparities in many areas of health status for individuals with mental retardation. Oral health disparities are of particular concern because of the impact of oral health on overall physical and mental health status. Poor oral health can result in eating problems, disturbed sleep, impaired speech, pain and lowered self-esteem. Coupled with other health conditions such as seizure disorders or diabetes, it can seriously complicate the management of those conditions. The challenge is to find new methods of health promotion and disease prevention that can overcome the environmental and social obstacles that often inhibit or preclude the use of preventive and health promotion services.

"This research project will evaluate customized versions of two products developed by [AbleLink Technologies](#), *Visual Assistant* and *Visual Impact*, to train, prompt and coach adults with mental retardation in more effective oral hygiene practices. The Pocket PC prompting technology, *Visual Assistant*, is a software package which can be customized to prompt and coach individuals with mental retardation through various tasks and activities using audio prompts and pictures representing each step in the task. For this project, the software both prompts the user to begin their program of oral hygiene health care at different times during the day and, using a sequence of linked audio messages and visual images, coaches them through the various steps involved in proper tooth brushing technique. *Visual Impact* is a computer-based training and task prompting system for teaching individuals with mental retardation new or difficult to learn tasks." [http://www.nymc.edu/wihd/speprojects/projects\\_health.html](http://www.nymc.edu/wihd/speprojects/projects_health.html)

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## NORTH CAROLINA

### **Count Us In project for health care professionals, lay health advisors, and women with disabilities**

“There were 5 activities involved in this project: 1) disability information/lectures /standardized patients were incorporated into the Duke curricula for students in nursing, physician’s assistants, and family medicine residency, 2) a disability teleconference was presented to the 16 SELF Improvement projects in NC, 3) the Breast and Cervical Cancer Screening lay health advisor training curriculum, developed by the NC Breast Cancer Screening Program, was reviewed and edited to become inclusive of women with disabilities, 4) utilizing the revised LHA curriculum, training on Breast and Cervical Cancer Screening was provided to lay health advisors in 5 selected SELF Improvement Projects, and 5) the women’s magazine, Orchid, was mailed to 5300 women with disabilities on Medicare in 21 NC counties that are home to SELF Improvement projects. Also, Removing Barriers to Healthcare and a Mammography Access Checklist were sent to mammography sites in these 21 counties.

Changes in knowledge and attitudes of providers were evaluated via questionnaires (multiple choice + case studies) administered before and immediately after participation in the project. Overall, participants demonstrated a gain in their knowledge about disability after the trainings. All learner groups continue to struggle with the care of persons with mental retardation. Based on feedback from trainers with disabilities, faculty, and students in the nursing and residency programs, the “lab” format seemed the most effective strategy used to present material.” <http://www.aahd.us/research/BestPractices/singletrainingHCP.php?ID=5>

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## OREGON

### **Oregon Office on Disability and Health**

<http://cdrc.ohsu.edu/oodh/about/index2.html>

OODH is primarily focused on promoting the health and wellness of people with disabilities and reducing the incidence of secondary conditions by: 1. Supporting health promotion activities that are grounded in contemporary public health methodologies. Examples include implementing the healthy Lifestyles Training Curriculum and the Personal Power training curriculum. 2. Conducting research activities that help ensure current and future public health activities are based on scientifically sound data and are meaningful to Oregonians with disabilities. Examples include funding and analyzing the Disability Module of the Oregon Behavioral Risk Factor Surveillance System (an annual random telephone survey of Oregonians on a host of health and wellness issues), and conducting the Oregon Community Assessment Survey. 3. Disseminating research findings and other information to diverse audiences such as policy makers, administrators, researchers and the general public. OODH has a quarterly newsletter, Disability & health Quarterly, which includes a data supplement, a policy brief series, several other publications, and teaches disability and public health courses in the Department



of Public health at OHSU. All OODH materials are available at our fully accessible website: <http://cdrc.ohsu.edu/oodh4>. Engaging in policy development activities such as devising policy and/or program recommendations and participation in local and statewide commissions, boards, and task forces that address disability, health, or wellness issues. The Community Engagement Initiative (CEI) is one example of a policy development activity. The CEI method consists of three steps: 1) “town-hall” meetings for people with disabilities and family members to identify local barriers to community accessibility and assets; 2) meeting with community leaders to describe the barriers; and 3) facilitating community responses to resolve access issues.

Contact:

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## PENNSYLVANIA

**Promoting Healthy Lifestyles for Adults with CP: Project GOOD (Growing Older Optimally with a Disability)** (<http://disabilities.temple.edu/programs/healthcare/phl/index.htm>)

With input from a cohort of advisors who are themselves aging with CP, project staff will design a curriculum and implement a training program to address the health-related needs of adults who are aging with Cerebral Palsy. Approximately 10 individuals will participate in each of the two four-month training cycles. Each cycle will consist of interactive trainings sessions, practical homework assignments, online activities and social support from peers and project staff. In addition, graduate students from various health care fields will be recruited to partner with individuals with disabilities participating in the program. By attending the training sessions together and working on health and wellness goals, student interns will learn from participants while providing social support. Anticipated outcomes for participants and student interns include the following: a) greater understanding of the interaction between aging and disability effects in daily life, b) improved awareness of the impact of lifestyle choices on the emergence or mitigation of secondary conditions, and c) increased familiarity with community resources that promote health and wellness. In addition, participant outcomes will include: a) improved ability to manage personal health care, b) greater confidence in ability to communicate with health care professionals, and c) increased confidence in ability to advocate for personal health needs. Student interns are also expected to show a greater confidence in their ability.

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Temple University

215-204-6749 (voice)

215-204-1356 (voice/TTY)

[edhealth@temple.edu](mailto:edhealth@temple.edu)



## WEST VIRGINIA

### **Rural Education for Appalachian Community Health at Home (REACH Home)** <http://www.cedwvu.org/programs/reach/>

“The goals of the REACH Home Project are:

- To improve statewide access to person-centered, quality home health care through the development and education of clinically competent health care professionals skilled in the interdisciplinary process and rural service delivery
- To improve access to a diverse and culturally sensitive health professions workforce” <http://www.cedwvu.org/programs/reach>

Contact:

Lori Risk, Program Manager  
304-293-4692  
[lcaterina@hsc.wvu.edu](mailto:lcaterina@hsc.wvu.edu)

## NATIONAL

### ***National Down Syndrome Society Changing Lives: Down Syndrome & the Health Care Professional Program***

“The *Changing Lives: Down Syndrome & the Health Care Professional Program* is designed to educate physicians, nurses, genetic counselors and other health care professionals on the clinical and developmental needs of people with Down syndrome and the best-care practices; prepare professionals to deliver diagnoses and other sensitive information; provide information on local and national resources; supply materials and information for new and expectant parents; foster on-going relationships between professionals and parents” <http://www.ndss.org/content.cfm?fuseaction=InfoRes.ChangingLives>.

Contact:

Changing Lives  
[info@ndss.org](mailto:info@ndss.org)  
800-221-4602  
212-460-9330

### **Supplemental Materials:**

A guide to good oral health for persons with special needs [http://www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Healthy\\_Athletes/Special+Smiles/Oral\\_Health\\_Guide/default.htm](http://www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Healthy_Athletes/Special+Smiles/Oral_Health_Guide/default.htm)

“Practical Oral Care for People With Developmental Disabilities Series

Designed to equip dental professionals with the basic information they need to deliver quality oral health care to people in the community with special needs. This includes instilling confidence not



only in treatment strategies, but also in the dental team's entire approach to the patient with developmental disabilities. There is also a guide for caregivers that explains their role at home in maintaining good oral health for their family member or client with special needs.” <http://www.nidcr.nih.gov/healthinformation/oralhealthinformationindex/developmentaldisabilities.htm>

- ☐ An Introduction to Practical Oral Care for People With Developmental Disabilities  
<http://www.nohic.nidcr.nih.gov/poc/publication/introduction.aspx>
- ☐ Continuing Education: Practical Oral Care for People With Developmental Disabilities  
<http://www.nohic.nidcr.nih.gov/poc/publication/general.aspx>
- ☐ Practical Oral Care for People With Autism  
<http://www.nohic.nidcr.nih.gov/poc/publication/Autism.aspx>
- ☐ Practical Oral Care for People With Cerebral Palsy  
<http://www.nohic.nidcr.nih.gov/poc/publication/cerebral.aspx>
- ☐ Practical Oral Care for People With Down Syndrome  
<http://www.nohic.nidcr.nih.gov/poc/publication/downSyndrome.aspx>
- ☐ Practical Oral Care for People With Mental Retardation  
<http://www.nohic.nidcr.nih.gov/poc/publication/mentalretard.aspx>
- ☐ Wheelchair Transfer: A Health Care Provider's Guide  
<http://www.nohic.nidcr.nih.gov/poc/publication/wheelchair.aspx>
- ☐ Dental Care Every Day: A Caregiver's Guide  
<http://www.nohic.nidcr.nih.gov/poc/publication/careguide.aspx>
- ☐ Ensuring Access to High Quality Health & Dental Care  
[http://www.nasddds.org/Meetings/2004\\_Annual\\_Meeting/2004\\_AM\\_presentations.shtml](http://www.nasddds.org/Meetings/2004_Annual_Meeting/2004_AM_presentations.shtml)



## HOUSING

The DD Act of 2000 defines “housing-related activities” as “advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.” (DD Act, 2000).

“Some of the advantages of consumer controlled housing include permanency, community inclusion, freedom, respect, responsibility, economic gain, location, choice, self-determination, and independence” (Arc of Minnesota & RTC on Community Living, 2000). <http://rtc.umn.edu/guide/>

“Home ownership and consumer controlled housing refer to a place to really call a home, that belongs to an individual, and for which the individual is responsible. Unfortunately, for individuals with disabilities, “home” often refers to a program with numerous regulations, paid staff, and restrictions. Control of one’s housing and ownership of real estate is power, not only within the individual’s immediate community, but within the larger American society.” ([http://www.aamr.org/Policies/faq\\_home\\_ownership.shtml](http://www.aamr.org/Policies/faq_home_ownership.shtml))

The state of Michigan has developed standards regarding best practices in housing for persons with mental illness that are applicable to persons with other disabilities. These standards assert that

- “Housing should blend into the community
- Policies should promote home ownership, choice, and autonomy
- Housing should be accessible
- Policies should be sensitive to cultural and ethnic preferences
- Policies should encourage and support consumer self-sufficiency
- Ongoing assessment of consumer’s housing needs should occur
- Assistance should be provided to coordinate resources to meet basic housing needs” (<http://www.marthachurchill.com/ddBPGhouse.htm>).

Successful housing strategies involve:

- “thinking ‘outside the box’ – using all available housing resources and not just those targeted to “special needs” populations”
- “While creativity is important, it must be balanced by feasibility. Successful strategies are feasible and concrete.”
- Determining “that a strategy will work in a particular housing environment or housing market.”
- Acknowledging that “many federal housing programs cannot be targeted to one subpopulation of people with disabilities (e.g., people with mental illness, people with mental retardation, people with physical disabilities, etc.). For this reason, partnerships and joint advocacy efforts among organizations that represent different disability populations can be very helpful when engaging housing officials in developing new housing strategies.” [http://www.tacinc.org/cms/admin/cms/\\_uploads/docs/opendoor12.08b.pdf](http://www.tacinc.org/cms/admin/cms/_uploads/docs/opendoor12.08b.pdf)



Some promising practices in housing include:

- ☐ rental subsidy programs (Hawaii)
- ☐ housing advocates (Louisiana)
- ☐ state registry of accessible housing (Massachusetts)
- ☐ home sharing (New York)
- ☐ self determination in housing (Pennsylvania)
- ☐ housing trust funds (Pennsylvania & New Jersey)
- ☐ supported living specialists (Wisconsin)
- ☐ information, referral, and subsidies (Wisconsin)
- ☐ reverse equity mortgages (National)

## **HAWAII (also Funding)**

### **Rental Subsidies**

<http://amh.health.state.hi.us/Public/News/AMHDnewsNov04.pdf>

“Another successful strategy for helping people with disabilities – particularly people living in restrictive settings who want to move into the community – is the development of a “bridge” rental subsidy program. Bridge rental subsidy programs use rental assistance resources – such as HOME or HOPWA tenant-based rental assistance or funding from human service agencies – to provide temporary rental assistance until a person receives a more permanent housing resource, such as a Section 8 voucher.”

“Bridge subsidies can help a person obtain affordable housing while they apply for and/or wait for a permanent housing subsidy. For a bridge subsidy program to be most effective, it should be modeled somewhat after the Section 8 program. For example, people using bridge subsidies usually have to pay a portion of their income toward rent (typically less than 50 percent of their income). Some bridge subsidy programs require people to pay more than they would pay in the Section 8 program as an incentive to accept the permanent Section 8 voucher when it becomes available.”

“In successful bridge subsidy programs, people who receive bridge subsidies are required to apply for a Section 8 voucher as soon as PHA waiting lists are open. Owners that accept bridge subsidies are asked to agree to accept the Section 8 voucher when the tenant finally receives one. This eliminates the need to look for new housing once the Section 8 voucher is obtained and addresses a barrier that many people with disabilities face in accessing and utilizing Section 8 vouchers.” <http://www.c-c-d.org/od-Dec03.htm#Strategy%20#1>



Contact:  
Department of Health  
Adult Mental Health Division  
PO Box 3378  
Honolulu, HI 96801-3378  
[www.amhd.org](http://www.amhd.org)  
Tel: (808) 586-4686  
Fax: (808) 586-4745

## **LOUISIANA**

### **Louisiana Community housing Advocacy Network**

“This project incorporates principles of social role valorization. That is, the project will recruit, hire, train, and support two individuals with significant disabilities to serve as housing Advocates. These individuals will be the primary point of contact between the project and the communities they serve. By the end of the project, an array of community housing options for individuals with disabilities and low-income, as well as programs and supports/services necessary to ensure that individuals with disabilities and low-income, have access to community housing options and will exist within participating communities. In addition, a network of key stakeholders concerned with community housing issues will be established within participating communities.” [www.aucd.org](http://www.aucd.org) NIRS database.

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Project Director  
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[www.hdc.lsuhs.edu](http://www.hdc.lsuhs.edu)  
Phone 504-942-7898 Fax 504-942-5908

## **MASSACHUSETTS**

### **Housing Registry**

“Finding accessible housing is often a time consuming, frustrating process for people with disabilities. People may need to contact several service agencies, public housing authorities, individual housing managers, and state agencies for information about accessible housing and existing vacancies that meet their needs. People with disabilities often place their names on waiting lists in several communities waiting for a vacancy.”

“The Commonwealth has addressed this challenge by developing a central registry for accessible housing that includes public housing, privately operated subsidized housing, and private market-rate developments. People with disabilities can access the registry on the Internet and by contacting the state’s Centers for Independent Living.”



“The Commonwealth’s legislature mandated the registry’s development as part of a law that established a Housing Bill of Rights for Persons with Disabilities. The main focus of the legislation was to ensure that all new housing construction and substantial rehabilitation was adaptable, and the law is similar to the federal Fair Housing Act... The law requires all property owners, managers and housing authorities to actively market units to people with disabilities. As implemented, the law requires owners with vacant accessible units to:

- Inform anyone who has notified them in the past 12 months that they need an accessible apartment that a vacancy exists; and
- Register vacant units with Mass Access and hold units open for at least fifteen days, during which the apartment may be rented only to a person who has a disability and needs the accessible features of the unit.” <http://www.cms.hhs.gov/promisingpractices/mahousing.pdf>

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617-204-3620

Lisa Sloane  
Massachusetts Rehabilitation Commission  
[lisa@adaptiveenvironments.org](mailto:lisa@adaptiveenvironments.org)  
413-243-9999

## NEW YORK

### **Home Sharing (began as senior program but now includes individuals with DD)**

“For more than a decade, home sharing for seniors has been gaining national recognition as an alternative to living alone or in a nursing home. More affordable than a nursing home, home sharing can provide companionship as well. The Foundation’s Home Sharing Program helps elder “hosts” with extra room in their homes or apartments link up with appropriate “guests” to share their space. The Foundation screens both parties, makes introductions and helps prospective hosts and guests gauge their compatibility for shared living. Once the host and guest agree to share living quarters, a “match” is made.

The enthusiasm of participants in the Home Sharing Program runs high. Both hosts and guests benefit from reduced housing costs and the possibility of companionship to offset the isolation and loneliness that many seniors experience. This program is funded by grants from the New York State Legislature, New York City Mayor’s Executive Budget, New York City Council Members and Borough Presidents, the New York State Office of Mental Retardation and Developmental Disabilities and the generosity of private foundations and donors.” [http://www.nyfsc.org/services/home\\_sharing.html](http://www.nyfsc.org/services/home_sharing.html)

Contact:

11 Park Place, 14th Floor  
New York, NY 10007-2801  
(212) 962-7559  
[nyfscinc@aol.com](mailto:nyfscinc@aol.com)



**PENNSYLVANIA (also Self-Determination)**

“In May, 1994 the Pennsylvania Developmental Disabilities Council funded Northwestern Human Services of Philadelphia to establish the Pennsylvania Self-Determination Housing Project (SDHP). In 1998, after four successful years, the project went on to form its own nonprofit corporation: Self-Determination Housing Project of Pennsylvania, Inc.

The mission of SDHP is to promote self-determination and control in housing for all people with disabilities in the Commonwealth of Pennsylvania.

The goal of the project is to build upon recent national and state efforts to increase the stock of affordable, accessible and integrated housing. By bringing together individuals committed to this goal, the project is expanding access to public and private housing programs and self-determination in housing for persons with developmental disabilities. The long-term legacy of the project will be an organized and dedicated group of people throughout the Commonwealth of Pennsylvania who understand the housing needs of persons with disabilities and who have the tools to address these needs” <http://www.sdhp.org/>

Contact:

SDHP, Inc  
119 South Easton Road  
Glenside, PA 19038  
215-884-2091

**PENNSYLVANIA & NEW JERSEY (also Funding)****Housing Trust Funds**

“Pennsylvania, through Act 137, has enabled 40 counties to create housing trust funds. New Jersey also encourages local housing trust funds and 142 municipalities have created local funds. Housing trust funds are distinct accounts that receive dedicated sources of public funds to support affordable housing. There are currently more than 275 housing trust funds in cities, counties, and states throughout the United States. They are providing at least \$750 million each year to support critical housing needs. Housing trust funds represent one of the most innovative and promising new initiatives in the struggle to address housing needs for all citizens.

The information presented in the report comes from the survey conducted in 2001. Additional information can be obtained on the progress report by contacting Mary Brooks at [Mbrooks@communitychange.org](mailto:Mbrooks@communitychange.org).” <http://www.acses.org/au-aug-2002-page3.html>

**WISCONSIN (also Funding)**



## Movin' Out

“Movin’ Out, Inc. provides training, information and referral, and housing counseling regardless of income, as its resources allow. Movin’ Out, Inc. provides housing subsidies and loans only to individuals and families with low or moderate income, as defined in HUD regulations.”

“Movin’ Out, Inc. provides services to people with a developmental, physical or mental disability or a combination of physical and mental impairments that:

- \* Are severe in degree
- \* Are expected to be of long-continued and indefinite duration
- \* Substantially impairs his or her ability to live independently as demonstrated by substantial functional limitations in one or more of the following areas of major life activity: Self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency
- \*Are not a result of the process of aging or the infirmities of aging AND
- \*Are of such a nature that functional limitations could be reduced or eliminated by more suitable housing conditions. More suitable housing conditions may or may not include potential of home ownership.

During the Loan application and underwriting process, Movin’ Out, Inc. gives priority for financial assistance to persons with disabilities that result in substantial functional limitations in three or more areas of major life activity, and that are characterized by the lifelong or extended need for individually planned and coordinated care, treatment or other services. Priority for services may be given to other individuals based on individual circumstances.” <http://www.movin-out.org>

Movin’ Out, Inc. has funding from “Dane County Human Services; State of Wisconsin, Division of Supportive Living, Department of Health and Family Services: Bureau of Community Mental Health; Wisconsin Council on Developmental Disabilities; United Way of Dane County; Federal Home Loan Bank of Chicago AHP funds; City of Madison— Department of Planning and Development/ Community Block Grant Program; Dane County—CDBG/HOME program; Wisconsin Partnership for Housing Development; State of Wisconsin Division of Housing and Intergovernmental Relations HOME program; The Joseph P. Kennedy Foundation” <http://www.movin-out.org>

Contact:

Toll free 1-877-861-6746 for consumers and families

E-Mail: [info@movin-out.org](mailto:info@movin-out.org)



**WISCONSIN**

“The State of Wisconsin employs a supported housing specialist who works with local communities to help people with disabilities and their families to find affordable housing solutions. In addition to assisting individuals in finding housing, the supported housing specialist works with individuals with disabilities and their families, local agencies, developers, real estate agents, housing providers, lenders, consumer groups and other stakeholders to build relationships among the parties to improve housing access for people with disabilities” (<http://www.cms.hhs.gov/promisingpractices/wisupport.pdf>) (p. 1).

“The state developed a supported housing initiative to address this need. The Wisconsin Council on Developmental Disabilities first funded a supported housing specialist to implement the initiative. The position is now funded through the Wisconsin Department of Health and Family Services. Persons eligible for assistance are children and adults on one of three Medicaid home and community-based services waivers that serve people with developmental disabilities or people with brain injuries.”

Contact:

Marcie Brost

(608) 266-9366

[brostmm@dhfs.state.wi.us](mailto:brostmm@dhfs.state.wi.us)

<http://www.dhfs.state.wi.us/bdds/housing.htm>

**NATIONAL (also Funding)****Reverse Equity Mortgages**

“The Reverse Equity Mortgage converts the cash value or equity of the family residence into cash that can be used for any purpose the homeowner decides. Families of adults with developmental disabilities could use these funds to purchase a home for their relative or to retrofit their home and provide much needed support services to bolster families’ caregiving.

The loan advances from reverse equity mortgages are not taxable and do not affect Social Security or Medicare benefits. All owners of the home must be at least 62 years old to be eligible. No payments on the Reverse Equity Mortgage are due while the owner continues to reside in the home. The mortgage becomes due when the owner dies, permanently moves out of the residence, or sells the home.

For more information contact the Fannie Mae Foundation at 1-800-471-5554 or your local or state chapter of the American Association of Retired persons (AARP), which has developed guide books.” Caldwell, Lopez, DeBrine, Factor, Heller, & Ennis <http://www.uic.edu/orgs/rrtcamlr/familyfuturesplanning.htm>



**NATIONAL****Multifamily Inventory of Units for the Elderly and Persons with Disabilities**

This inventory is designed to assist prospective applicants with locating units in HUD insured and HUD subsidized multifamily properties that serve the elderly and/or persons with disabilities.

<http://www.hud.gov/offices/hsg/mfh/hto/inventorysurvey.cfm>

Illinois inventory <http://www.hud.gov/offices/hsg/mfh/hto/state/il.pdf>

**SUPPLEMENTAL MATERIALS:**

- ☐ Fact Sheet: Home Ownership [http://www.aamr.org/Policies/faq\\_home\\_ownership.shtml](http://www.aamr.org/Policies/faq_home_ownership.shtml)
- ☐ Going it Alone [http://www.tacinc.org/cms/admin/cms/\\_uploads/docs/GoingitAlone.pdf](http://www.tacinc.org/cms/admin/cms/_uploads/docs/GoingitAlone.pdf)
- ☐ Solutions that Work: Innovative Strategies to Meeting the Housing Needs of People with Disabilities [http://www.tacinc.org/cms/admin/cms/\\_uploads/docs/opendoor12.08b.pdf](http://www.tacinc.org/cms/admin/cms/_uploads/docs/opendoor12.08b.pdf)
- ☐ Piecing it all together in your community: Playing the housing game. Learning to use HUD's consolidated plan to expand housing opportunities for people with disabilities [http://www.tacinc.org/cms/admin/cms/\\_uploads/docs/FINAL.pdf](http://www.tacinc.org/cms/admin/cms/_uploads/docs/FINAL.pdf)
- ☐ The Center for Housing and New Community Economics (CHANCE) <http://chance.unh.edu/>
- ☐ A Home of Your Own Guide — A resource for housing educators and counselors to assist people with disabilities [http://www.efanniemae.com/hcd/single\\_family/mortgage\\_products/own.html](http://www.efanniemae.com/hcd/single_family/mortgage_products/own.html)
- ☐ Pooled Trust Programs for People with Disabilities – A Guide for Families [http://www.uic.edu/orgs/rrtcamr/300005\\_PooledtrustPrograms.pdf](http://www.uic.edu/orgs/rrtcamr/300005_PooledtrustPrograms.pdf)
- ☐ Exploring the Opportunities: Affordable, Accessible, and Integrated Housing 101-Parts 1&2 [http://www.hcbs.org/moreInfo.php/topic/206/ofs/10/doc/75/exploring\\_the\\_Opportunities:\\_\\_Affordable,\\_Accessib](http://www.hcbs.org/moreInfo.php/topic/206/ofs/10/doc/75/exploring_the_Opportunities:__Affordable,_Accessib)
- ☐ Technical Assistance Collaborative (TAC) Boston, Massachusetts <http://www.tacinc.org/index/> TAC collaborates with the Consortium for Citizens with Disabilities Housing Task Force to provide technical assistance and training.
- ☐ The Report on Housing - “an in-depth look at housing issues facing people with disabilities. It shows that people with disabilities have difficulty obtaining housing primarily because housing is not affordable, not available, and not accessible.” [http://olrs.ohio.gov/asp/pub\\_HousingGuides.asp#part1](http://olrs.ohio.gov/asp/pub_HousingGuides.asp#part1)



- ❑ Information on Housing – “This guide provides information useful to people who need housing, or to anyone who wants to help people who need housing.”  
[http://olrs.ohio.gov/asp/pub\\_HousingGuides.asp#part2](http://olrs.ohio.gov/asp/pub_HousingGuides.asp#part2)
- ❑ Advocating for Housing – “This guide describes how to advocate to make housing more affordable, available, and accessible, with information and advocacy ideas.”  
[http://olrs.ohio.gov/asp/pub\\_HousingGuides.asp#part3](http://olrs.ohio.gov/asp/pub_HousingGuides.asp#part3)
- ❑ Home Control Through Trust and Estate Planning (discretionary trusts/special needs trusts)  
<http://www.altonweb.com/cs/downsyndrome/index.htm?page=homecontrol.html> \*This project was supported by the Illinois Council on Developmental Disabilities



## LEADERSHIP DEVELOPMENT

The DD Act of 2000 states that state councils on developmental disabilities shall “support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions; and”

“The Council may support and conduct activities to educate the public about the capabilities, preferences, and needs of individuals with developmental disabilities and their families and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, education of policymakers, and citizen leadership skills.” (DD Act, 2000). ( <http://www.acf.hhs.gov/programs/add/DDB.htm>)

AAMR defines leadership as “when a person learns the skills they need to run a group or be a part of a board or committee. It is also speaking up for yourself and helping each other learn how you can work together as a TEAM (Together Everyone Achieves More). It is learning new things and sharing what you have learned with others. Leaders also know how to listen to people when they are talking and know when a person might need support. Leadership sometimes is letting other people take over a discussion and have a chance to practice being a leader while they are learning new skills. Being a leader is being a part of the community and knowing what is going on and getting involved. Leadership means a lot of different things to a lot of people so it is important for people to figure out what is best for them” (AAMR website).

Promising practices in the states include:

- ☐ interdisciplinary Leadership Education in Neurodevelopmental Disabilities Projects (LENDs)—there are currently 35 LEND programs in 29 states
- ☐ men’s peer-to-peer support network (Delaware)
- ☐ online DD Leadership Forum (Massachusetts)
- ☐ participatory leadership training of self-advocates, services providers, parents, professionals and other allies (Minnesota)
- ☐ web-based Partners in Policymaking (Minnesota)
- ☐ leadership mentoring in rural CILs (Montana)
- ☐ self-advocates teaching family members, friends, and professionals about self-advocacy (North Carolina)
- ☐ self-advocates influencing policy and legislation (Oregon)



- ☐ national cadre of youth leaders (Oregon)
- ☐ legislative coalition (Utah)
- ☐ Leadership Development Center (Washington DC)
- ☐ youth leadership forum for students with disabilities (Washington DC)
- ☐ leadership training by self-advocates (National)
- ☐ leadership training initiatives in higher education (AK, HI, IL, LA, MA, MO, NE, NC, NH, OR, & WI)

## **ARKANSAS**

### **Leadership Education in Neurodevelopmental Disabilities**

“The Interdisciplinary Leadership Education in Neurodevelopmental Disabilities Project (LEND) is supported by a grant from the U.S. Maternal and Child Health Bureau. The LEND program provides an interdisciplinary clinical and didactic experience with an emphasis in Leadership education. Project staff assist LEND trainees in attaining high levels of clinical competence as well as developing Leadership attributes including a focus on populations needing service, systems of care, community-based services, program administration, public policy, and research.

Trainees will participate in theoretical and practical training in neurodevelopmental disabilities, working with children and their families, service providers, and other representatives of the service system. The program includes participation on interdisciplinary clinical teams, experiences in the community, research opportunities, and attendance at in-house seminars and conferences. In addition, trainees are exposed to and are expected to participate in providing technical assistance to programs offering services in the community. Participation on professional organization or agency boards or committees, and participation at professional conferences is also encouraged.

#### **Purpose and Goals**

The purpose of the training is to prepare trainees to assume Leadership roles that enhance systems of care for children with special health care needs and their families. As a result of LEND activities, trainees are better prepared to assist children and their families to achieve their self-determined goals and developmental potentials by forging a community-based partnership of health resources and community Leadership. The project prepares leaders in the field of neurodevelopmental and related disabilities, to teach principles of family-centered, community-based coordinated care practices, and to promote the values guiding Partners’ mission to create and preserve a quality of life for people with disabilities and their families.” [www.aucd.org](http://www.aucd.org) NIRS database

#### **Contact:**

Mark Swanson  
501-682-9903  
[www.uams.edu/uap](http://www.uams.edu/uap)



**DELAWARE****Men's Leadership Project**

“In an effort to support fathers, a Men's Support Network is being developed in Delaware. To develop this Network effectively, the state will need a large corps of men's leaders who are committed to men, boys, and families. Men who are responsible, can build good relationships with other men, and who are willing to learn the skills needed to successfully carry out activities that will be attractive to males and that support them to achieve the lives they want for themselves, their families, and their communities.

A unique non-credit, non-graded certification training is being offered for men who are already working in the community with males or who are interested in such work and have the potential to learn to do it well. The Spring 2003 class will focus on male leaders committed to the Head Start community and to the well-being and success of children from low-income neighborhoods.

Class participants are expected to play an active, thoughtful role in supporting other men involved in the training. Certification will be awarded to participants who complete the training, which includes a Tuesday evening course and one weekend workshop. At the completion of the training participants can continue to meet with other men's leaders and become a part of the larger Men's Leaders Network.

The training will cover a large range of topics including skills and insights necessary for setting up activities that appeal to fathers and young men.” <http://www.udel.edu/cds/fatherhood.html>

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**MASSACHUSETTS****Developmental Disabilities Leadership Forum**

“The mission of the Developmental Disabilities Leadership Forum is to create a “virtual learning organization” located on the World Wide Web. The Forum is designed to provide a variety of distance learning courses in addition to several Internet-based communication mechanisms that will allow participants to debate, discuss and critically analyze services, policy, research and a variety of other issues facing individuals with disabilities and their families.

The Developmental Disabilities Leadership Forum consists of four separate but integrated instructional elements. Each element is designed to interact with and compliment each of the other elements.



### 1. Distance Learning Courses

Five distance learning courses have been developed by Shriver Center faculty or faculty at affiliated MCHB training projects in the Boston area. Distance learning courses will address the following MCH priority topics: Universal Newborn Hearing Screening, Genetics, Children with Special Health Care Needs, Attitudes and disability, and Developing Culturally Competent Services for Children With Developmental Disabilities.

### 2. Discussions

“Ask the Expert” sessions are designed to serve as informational exchanges with leaders in the field of developmental disabilities.

Threaded Discussion is directed at general topics in developmental disabilities as well as specific topics covered in each of the distance learning courses.

### 3. On-line Journal

Leadership Perspectives in Developmental Disabilities will be the first on-line journal devoted exclusively to professional and Leadership issues in developmental disabilities.

### 4. Internet Conferencing

This site will host conferences focusing on topic areas that effect developmental disabilities leaders working at the regional and national level.”[www.aucd.org](http://www.aucd.org) NIRS database

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## MINNESOTA

### Common Vision

“Common Vision is a participatory leadership program that builds knowledge and creates sustained leadership within the disability community.

Participants include self-advocates, service providers, parents, professionals, and other allies working together to create a shared vision of the future. Through highly participatory lessons in history, community organizing, issue identification, and leadership development, participants discover their own power and learn methods for creating change in their communities.

Common Vision connects participants to the history of people with disabilities, to broader disability rights movements, and to other civil rights struggles, developing the knowledge based and skills needed for both individual advocacy and systems change organizing. The program has been effective in increasing the visibility of people with developmental disabilities within the disability community, increasing awareness about poverty as a disability issue, and building coalition work with other social change groups.

Common Vision uses a variety of approaches — music, slide presentations, small-group discussions, video, and participatory exercises — to ensure that everyone participates and contributes to a shared



learning process. Workshops are tailored to the specific needs of the participants.” [www.aucd.org](http://www.aucd.org) NIRS database

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## MINNESOTA

### Partners in Policymaking

“Partners in Policymaking is a value-based and competency-based leadership training for parents of young children with developmental disabilities and adults with disabilities. The program teaches leadership skills and best practices, and develops the competencies of participants so they can effectively influence public policy at all levels of government. The Council is committed to the future leadership of people with developmental disabilities, those individuals with the first hand experience and expertise to know what works/doesn’t work in service delivery systems. Partners is committed to increasing the independence, productivity, integration and inclusion of the program participants.

Since 1987, Partners programs have been implemented in 46 states funded by the Developmental Disabilities Assistance and Bill of Rights Act. More than 8,600 Partners graduates are part of a growing national network of community leaders serving on policy making committees, commissions, and boards at local, state, and national levels.

Minnesota’s partners in policymaking involves online training curriculums including:

- “Partners in Education,” a three-hour self directed e-learning course to help parents with children with developmental disabilities better understand and maximize the benefits of special education services and inclusion for their children”;
- “Making Your Case” ...a three hour self directed course on how to communicate with public officials by effectively telling your personal story, writing a letter, providing testimony, and communicating in positive ways”;
- “Partners in Employment” ...a six hour self directed course on how to find a job, write a resume, participate in an interview, and plan for your career”

There is no charge for the “Partners in Education” or “Partners in Employment” courses. The “Making Your Case” curriculum is offered for \$30.” [www.aucd.org](http://www.aucd.org) NIRS database

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**MONTANA****Rural Independent Living Leadership Mentoring Initiative**

“The Rural Independent Living Leadership Mentoring Initiative (RILLMI) addresses the need for rural CIL capacity-building. The efficient and effective operation of CILs is a complex undertaking. The emphasis on consumer power and control, the realization that equitable workplaces create leaderful organizations, a need for cultural diversity, the necessity for strong governance, shrinking state and local resources, the challenges of managed care and various government/taxpayer initiatives, the paucity of rural Transportation, the pressing need for interagency, business and community collaboration (Civic Entrepreneurship), rising direct service personnel turnover rates, and the all encompassing push of systems change make management more and more difficult. Add to this situation the fact that many CIL leaders, at all organizational levels, have little opportunity for consistent, sequenced management training that teaches capacity building and resource leveraging, and the need for a mentoring system becomes evident.

RILLMI will establish a developmental resource by competitively identifying two CILs annually to receive sequenced, agency-specific training. Over the 5 project years, 10 organizations nationally will receive high quality, cost-effective Mentoring. The Rural Institute and APRIL will provide frequent and recurrent on-site consultation in each organization. A 6-step approach to mentoring will be applied. Phase One refines Values and Mission. Phase Two addresses Corporate Culture. Phase Three teaches Management & Supervision skills. Phase Four is focused on agency Communication and Conflict Management. Phase Five builds Team Work capacity. And Phase Six develops approaches to Personnel Evaluation, Staff Recruitment, and Reward Systems.

A variety of classroom and distance education activities will be conducted. The RILLMI will:

- Conduct a series of National training sessions based upon identified rural CIL staff development needs including Social Security Work Incentives; Peer Counseling Techniques; Community Building and Advocacy, Rural Transportation options, Fund Raising, Rural Housing, Self-Advocacy development, Board recruitment & refinement, et al.;
- Will provide extensive Technical Assistance delivered on-site by Peer Consultants, on-line, and through phone consultation;
- Will support national Dissemination of contemporary materials in accessible formats.

The RILLMI will also establish an Executive Leadership Forum on the Internet for communication among CIL leaders and will sponsor numerous national Teleconferences. A variety of continuing education collaborative events with other rehabilitation training and research projects and community entities will significantly augment the impact of the RILLMI.” [www.aucd.org](http://www.aucd.org) NIRS database

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**NORTH CAROLINA (also Self-Advocacy)****Steps Toward Independence and Responsibility**

“STIR (Steps Toward Independence and Responsibility) is a project team at the Center for Development and Learning at the University of North Carolina, Chapel Hill. It is run for and by people with developmental and other disabilities. STIR workshops build knowledge and help create Leadership options for people with disabilities. STIR offers training directly to self-advocates, parents, family members, friends, and professionals. STIR uses a variety of approaches including slide presentations, small group discussions, video and hands-on FUN activities. Topics of workshops include:

- How to be a good self-advocate
- How to start a self-advocacy group
- Keeping a self-advocacy group going
- Basic principles and guidelines of self-determination

Includes a historical perspective of where self-determination came from and a basic understanding of what self-determination means for a person with a disability and for the system as a whole. Each workshop trains 15 participants.” [www.aucd.org](http://www.aucd.org) NIRS database

“Shifting the Power is a collaborative project among STIR, [that] provided training and technical assistance on self-advocacy, self-determination, and leadership to self-advocate leaders and their allies in 10 states and/or U.S. territories in an effort to shift the power to self-advocates. The Speak Up! Guide developed by STIR and Shifting the Power, was the primary resource used in the project. States interested in this training opportunity were required to provide evidence of need for training and agreed to provide the training to other people with developmental disabilities who do not typically have access to leadership training due to language barriers, cultural differences, or restricted living environments (such as institutions or nursing homes).” <http://www.cdl.unc.edu/stir/shifting/aboutShifting.asp>

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## **OREGON (also Self-Advocacy)**

### **Self-Advocates as Leaders**

“Self-Advocates as Leaders (SAAL) is a coalition of self-advocates interested in developing Leadership skills and becoming equal partners in policy and legislation which affect self-advocate’s lives. SAAL is currently working on a number of goals, including member Leadership development, advising the State Seniors and People with Disabilities Division on Self-Directed Supports and Universal Access, and conducting training and technical assistance projects such as My Voice, My Voice and Voter education training for self-advocates across the State. Self-Advocates as Leaders is a growing group that is organizing additional leaders in various areas of Oregon. SAAL’s planned activities include hiring a self-advocate Director, Board and Committee development, establishing a SAAL office and becoming a private, non-profit organization.

The purpose of the Empowerment-Self Advocates as Leaders Project is to provide SAAL with administrative and technical support for moving forward its vision and accomplishing its goals. The Project is conducted by The National Center for Self-Determination and 21<sup>st</sup> Century Leadership at the OHSU Center on Self-Determination. Supporting SAAL is directly related to the National Center’s mission of promoting the self-determination and Leadership of people with disabilities.

SAAL [will] build a community of informed and active self-advocate leaders that are shaping policy and creating new opportunities for citizens with disabilities across Oregon.” [www.aucd.org](http://www.aucd.org) NIRS database

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Self-Advocates as Leaders NOTE: The Leadership Network is also in Utah, New Hampshire, Illinois, North Carolina, Missouri, Colorado, Oklahoma, Arizona, Texas and Massachusetts.

## **OREGON**

### **National Youth Leadership**

“The National Center on Self-Determination at Oregon Health Sciences University, in partnership with the Academy for Educational Development and youth leaders across the nation, will establish a National Youth Leadership Development Network, with the purpose of supporting a national cadre of youth leaders with disabilities who can inform the design of educational and other policies and practices toward young people with disabilities. The National Youth Leadership Development Network will build upon prior activities aimed at developing a national community of youth leaders who can inform professionals, parents, educators, and employers, as well as move forward an agenda that fosters youth self-determination and transition success in states, territories, and communities across the nation. The Network will convene an annual National Youth Leadership Summit that will



bring together a diverse group of young leaders with a variety of disabilities, ages 16 - 24, from across the U.S. Summits will focus on topics such as equality of opportunity and self-sufficiency, disability history and civil rights, skills for effective leadership, self-determination, independent living. Summit outcomes will include the identification of key barriers, promising practices, and recommendations for actions, as well as an increase in the knowledge and skills the youth leaders can take back to their communities to effect change. Young people with disabilities will be leaders in all aspects of Network planning, implementation, evaluation, and dissemination. Network activities will be coordinated with youth development initiatives underway involving youth with and without disabilities. Network activities will include a Web site with a bulletin board, topical teleconferences, a newsletter, an electronic leadership discussion group, mentoring and peer support, ongoing technical assistance, and youth participation in state and national policy and leadership initiatives.”  
[http://www.ku.edu/cgiwrap/tcacs/grantsearch/viewgrant.php?grant\\_id=644](http://www.ku.edu/cgiwrap/tcacs/grantsearch/viewgrant.php?grant_id=644)

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## **UTAH**

### **Legislative Coalition for People with Disabilities Project**

“The Utah Legislative Coalition for People with Disabilities Project is supported by many disability organizations in Utah, including the CPD, the Governor’s Council for People with Disabilities, the Disability Law Center, state disability service agencies, and consumer groups. The Coalition was organized in 1987 to provide Leadership, training, coordination, and technical assistance to parents, advocates, and advocacy organizations about disability legislation. This training and technical assistance includes information about the Utah legislative process, how legislation becomes law, and how to work with legislators. The Coalition identifies legislation which will improve services and programs for citizens with disabilities and tracks these bills through the legislative session. Training and technical assistance on legislative issues and state appropriations are also provided to the legislature. Information generated by the various research and demonstration activities of the CPD is used as appropriate by Coalition members and the Utah State Legislature.” [www.aucd.org](http://www.aucd.org) NIRS database

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**WASHINGTON DC****Center for the Study and Advancement of Disability Policy**

“The Center for the Study and Advancement of Disability Policy conducts research and analysis of complex public policy issues affecting individuals with disabilities and their families. Through consensus-building strategies that transcend partisan and interest-group politics, the Center develops common-sense, flexible solutions that recognize the needs and rights of individuals with disabilities and their families as well as the legitimate concerns of Federal, State, local, and private entities.

The Center also provides public education, leadership development and training, technical assistance and information dissemination to disability groups, international, national, State, local, and private sector leaders and others interested in learning about the complex details of, and the relationships among various laws and programs affecting individuals with disabilities and their families.

More specifically, the Center:

- Conducts research and analysis of disability policy issues and translates research into policy alternatives related to current issues affecting Federal, State and local governments and the private sector;
- Creates educational and training opportunities for individuals with disabilities and their families, international, national, State, and local leaders, advanced policy fellows and others to learn about the complex details of, and the relationships among various laws and programs affecting persons with disabilities and their families;
- Provides a national forum for discussion of public policies affecting persons with disabilities and their families;
- Provides technical assistance and disseminates policy information to organizations representing disability groups, professional groups, and Federal, State, local, and private entities that want to devise solutions to complex policy issues that require a broad-based consensus.” <http://www.disabilitypolicycenter.org/about.htm>

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**WASHINGTON DC****Youth Leadership Forum for Students With Disabilities**

“The Youth Leadership Forum for Students with Disabilities (YLF) is a unique career leadership training program for high school juniors and seniors with disabilities. By serving as delegates from their communities at a four-day event in their state capital, young people with disabilities cultivate leadership, citizenship, and social skills.



Delegates gain access to vital resources related to assistive technology, community support, and civil rights. Successful men and women with disabilities serve as role models in helping youth realize their ability, right, and obligation to pursue meaningful employment and contribute to society.

The educational and motivational forum involves an intense schedule. Throughout the training, small “working groups” explore personal leadership and career plans. Social, artistic, athletic, and recreational activities abound, as these are part of leading a well-rounded life. Guest speakers address such topics as disability rights laws, innovations in technology, and resources at all levels. A guided tour of the state capitol involves interaction with members of the press, government dignitaries, and often the governor. A farewell dance is a time to celebrate accomplishments with new friends.

The key to the YLF is leadership by example. Adults with disabilities who have traveled the same path these young people are facing serve as faculty and staff. Many other volunteers, some with disabilities and some without, help to make the program a success.

YLF alumni take with them an obligation to follow through on goals outlined in “personal leadership plans” that they have written for themselves. In California, past participants of this program have developed an alumni newsletter to share resources. In addition, follow-up activities including corporate mentorships and internships have been established in order to continue networking activities. Often alumni return to the YLF in later years as volunteer staff.” <http://www.dol.gov/odep/programs/ylf.htm>

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### **NATIONAL (also Self-Advocacy)**

#### **Using the 7 Habits of Highly Effective People – Capabilities Unlimited and Rehabilitation Research and Training Center on Aging with Developmental Disabilities**

The 7 Habits of Highly Effective People (Covey, 1989) is among the most popular and widely applied leadership development workshops. The 7 Habits include: 1) Be Proactive; 2) Begin with the End in Mind; 3) Put First Things First; 4) Think Win-Win; 5) Seek First to Understand Then to Be Understood; 6) Synergize; 7) Sharpen the Saw. Foundational principles of the 7 Habits promote interdependence and the development of mission statements that assist individuals to envision and attain personal goals.

The principles of the 7 Habits were adopted to develop an innovative leadership workshop for individuals with developmental disabilities, Using the 7 Habits of Highly Effective People (Pederson & Nelis, 2003). This workshop is a 2-day workshop that uses accommodating materials and activities for individuals with developmental disabilities to communicate principles. It is co-facilitated by individuals with developmental disabilities who are certified trainers through the Franklin Covey Institute.



Individuals with developmental disabilities often have few opportunities to make daily choices in their lives (Heller, Sterns, Sutton, & Factor, 1996; Lakin, Burwell, Hayden, & Jackson, 1992) and fewer opportunities to develop leadership skills through such means as group participation in school activities and mentoring experiences (Pederson, 1997). The self-advocacy movement has provided pathways of empowerment for individuals with disabilities and promoted opportunities for leadership (Miller & Keys, 1999). Many individuals have assumed elected positions and served on decision-making boards and committees, within the self-advocacy movement as well as within their local communities (Pederson, 1997; Powers, Ward, Ferris, Nelis, Ward, Weick, & Heller, 2002; Wehmeyer & Berkoben, 1996). As individuals with developmental disabilities secure more and more positions of leadership, it is important that opportunities for continuing education and reflection are created that assist individuals in personal and professional development. Applying foundational principles of the 7 Habits can assist individuals with developmental disabilities to become more effective self-advocates and leaders.

- Covey, S.R. (1989). *The 7 Habits of Highly Effective People: Powerful Lessons in Personal Change*. New York: Fireside.
- Heller, T., Sterns, H., Sutton, E., & Factor, A. (1996). Impact Of Person-Centered Later Life Planning Training Program For Older Adults With Mental Retardation. *Journal of Rehabilitation*, 62, 77-83.
- Lakin, K.C., Burwell, B., Hayden, M., & Jackson, M. (1992). *An Independent Assessment Of Minnesota's Medicaid Home And Community Based Services Waiver Program (Report No. 37)*. Minneapolis: University of Minnesota, Center for Residential Services and Community Living, Institute on Community Integration.
- Miller, A.B. & Keys, C.B. (1996). Awareness, Action, And Collaboration: How The Self-Advocacy Movement Is Empowering For Persons With Developmental Disabilities. *Mental Retardation*, 34(5), 312-319.
- Pederson, E. (1997). Including Self-Advocates In Community Leadership. *Disability Solutions*, 2(4), 1-9.
- Pederson, E. & Nelis, T. (2003). *Using the 7 Habits of Highly Effective People*. Chicago, IL: RRTC on Aging with Developmental Disabilities, University of Illinois at Chicago.
- Powers, L.E., Ward, N., Ferris, L., Nelis, T., Ward, M., Weick, C., & Heller, T. (2002). Leadership By People With Disabilities In Self-Determination Systems Change. *Journal of Disability Policy Studies*, 13(2) 125-133.
- Wehmeyer, M. & Berkoben, R. (1999). The Legacy Of Self-Advocacy: People With Cognitive Disabilities As Leaders In Their Community. In G. Dybwad & H. Bersani (Eds.), *New Voices: Self-Advocacy by People with Disabilities* (pp. 245-257). Cambridge, MA: Brookline Books.

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## **SELF-ADVOCACY**

Self-Advocates Becoming Empowered (SABE) defines self-advocacy as:

It is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in (Hayden & Nelis, 2002).

Histories written about the Self-Advocacy Movement generally date the movement back to developments in Sweden during the 1960s and the initial work of Bendt Nirje (Dybwad, 1996). In 1974, People First of Oregon became the first self-advocacy group in the United States, inspired from a conference in Canada. By 1990, development of a national organization began to form. Self-advocates from 38 states met at the first North American People First Conference in Estes Park, Colorado. Despite pressure from professionals, self-advocates decided to move slowly and cautiously. It eventually took nearly 4 years of planning to accomplish the goal of a national organization. Steering committee meetings were held in Chicago, sponsored in part by the Institute on Disability and Human Development at the University of Illinois at Chicago. Self-Advocates Becoming Empowered (SABE) became incorporated in 1994 at the third National Self-Advocacy Conference in Alexandria, Virginia.

In 2002, there were over 800 self-advocacy chapters in the United States and chapters within 43 other countries (Hayden & Nelis, 2002). In stark contrast to the Independent Living Movement, these chapters generally receive very little outside funding, particularly federal funding. Chapters exist primarily on a volunteer, grassroots level. Some state organizations have been able to secure some funding to hire limited amounts of staff or advisors. However, there still are not state chapters in every state. Approximately 31 states have organized at the state level and an additional 9 have state-level contacts (Hayden & Nelis, 2002).

The Self-Advocacy Movement has contributed to the development of many promising practices. The three projects selected here represent projects that have collaborated with the Self-Advocacy Movement. These projects involve self-advocates in supporting others individuals with developmental disabilities through providing opportunities to develop skills, meaningful experiences, and personal life goals.

## **References**

Dybwad, G. (1996). Setting the stage historically. In G. Dybwad and H. Bersani (Eds.), *New Voices: Self-Advocacy by People with Disabilities*, pp. 1-17. Cambridge MA: Brookline Books, Inc.

Hayden M., & Nelis, T. (2002). Self-Advocacy. In R.L. Schalock, P.C. Baker, \* M.D. Croser (Eds.), *Embarking on a New Century: Mental Retardation at the End of the 20<sup>th</sup> Century*, pp. 221-233.



## GEORGIA

### **Everyone Can Serve Project –SABE and University of Georgia Institute on Human Development and Disabilities**

Self-Advocates Becoming Empowered (SABE) and the University of Georgia Institute on Human Development and Disabilities received a grant from the Corporation for National Service. Corporation for National Service runs the Ameri Corps, VISTA, Senior Service and Learn and Serve program in the states. These are volunteer and service opportunities whose benefits include monthly stipends and educational awards. SABE worked with the National Service Programs in Georgia, Alabama, Louisiana, and Mississippi in Region 6, to help them learn how to include and support people with cognitive disabilities in national service programs. We also helped in recruitment, support and accommodation needed for self-advocates to participate. Many of the members of SABE have been involved in Americorps and VISTA as organizers for state self-advocacy chapters. State self-advocacy organizations have also served as project sites for Americorps and VISTA, including Tennessee, Oklahoma, New York, Missouri, Georgia, and Utah. These projects have focused on building self-advocacy in each state, and resulted in some of the strongest self-advocacy organizations in the nation. James Meadours was a VISTA volunteer in Oklahoma for two years. According to James, his work with VISTA provided the opportunity to continue his involvement with self-advocacy by moving into the role of a community organizer. He also gained much self-confidence in his skills as a leader and feels this has led to his current career as a Self-Advocacy Facilitator for the Louisiana Self-Advocacy Project. The model developed by SABE and the University of Georgia could be expanded to other areas of the country.

They produced the following publication: EVERYONE CAN SERVE! (2003) — A videotape and presentation guide to help recruit, include, and support people with cognitive disabilities in national service and community volunteering. Although these products were designed for self-advocacy organizations, others also will benefit from learning how self-advocates may assume leadership roles. (Video, VHS, open captioned, 1 hr. 17 min.; Guide, 96 pages including overheads; video and guide, \$49.95 postpaid)

For more information:

<http://www.sabeusa.org/ecsp.html> (SABE's website)

[http://www.uap.uga.edu/main\\_menu.php?CID=11&DID=4](http://www.uap.uga.edu/main_menu.php?CID=11&DID=4) (University of Georgia Institute on Human Development and Disability)



**GEORGIA (also Transition)****ADA and Self-Advocacy in the High Schools**

Although the Americans with Disabilities Act (ADA) guarantees civil rights protection for youth with disabilities seeking employment and post secondary education, many high school students and their teachers are still unaware of the provisions of this landmark legislation. Georgia's project focuses on educating high school students with disabilities about transition from high school to college and/or employment. Activities of this project include: conducting focus groups with students and teachers to identify their interests and needs, sponsoring training events to provide students and teachers with information about the ADA, introducing students to self-advocacy and People First, Inc., and inviting adults with disabilities to speak to students about their jobs and their lives in the community. Through this project high school students in Clarke and surrounding counties in Georgia will learn to speak for themselves, know their rights under the ADA, meet role models from their communities, and learn about People First of Georgia. The project will also help teachers to better understand the ADA (ADD Update, December 2004).

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**NATIONAL (also Leadership)****Self-Advocacy Leadership Network**

The Self-Advocate Leadership Network, established in 1998, is a collaboration between self-advocate from across the country and the Human Services Research Institute (HSRI). They offer training directly to self-advocates and others - including family members, direct support staff and board members. They developed a curriculum called "My Voice, My Choice - A Manual for Self-Advocates." "My Voice, My Choice" emphasizes basic skills and information related to self-advocacy, how service systems work, and self-determination. The curriculum is designed in a way that makes the information easy to learn and fun. It uses ordinary language, group activities, puzzles, overheads, and more to help people learn and remember the information. In addition, they provide training on other topics. These topics include planning and giving a presentation, establishing an AmeriCorps\*VISTA project for self-advocates, and using Medicaid to fund trainings for self-advocates. The training is a great resource for family members, board members, direct support staff and others! Most recently they developed a newsletter called The Riot! This project serves as a national model for building a network of leaders from the self-advocacy movement to provide training and assistance to others. It could also serve as a model for states.



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<http://www.hsri.org/leaders/about.htm> (HSRI)

<http://www.hsri.org/leaders/theriot/> (The Riot newsletter)



## SELF-DETERMINATION

According to the DD Act of 2000, “The term ‘self-determination activities’ means activities that result in individuals with developmental disabilities, with appropriate assistance, having-

- A) the ability and opportunity to communicate and make personal decisions;
- B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;
- C) the authority to control resources to obtain needed services, supports, and other assistance;
- D) opportunities to participate in, and contribute to, their communities; and
- E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities” (DD Act, 2000).

(Quoted from the Developmental Disabilities Assistance and Bill of Rights Act of 2000; Available at: <http://www.acf.hhs.gov/programs/add/DDA.htm>)

“Self-Determination is the ability for people to:

- control their lives
- reach goals they have set
- take part fully in the world around them”

“Self-Determination has four basic rights and responsibilities:”

- Freedom,
- Control of own life
- Chosen Supports
- Community Involvement

(Quoted from website of Center on Self-Determination at the Oregon Institute on Disability and Development; About Us; Available at: <http://www.selfdeterminationohsu.org/>)

## A BROAD OVERVIEW OF SELF-DETERMINATION THROUGH REPORTS

### I. The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report

Bradley, V., Agosta, J., Smith, G., Taub, S., Ashbaugh, J., Silver, J., & Heaviland, M. (November, 2001). The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report. Available: <http://www.hsri.org/docs/767aRWJFinalImpactAssessmentReport.PDF>.

Bradley, V.J., Agosta, J., Taub, S., Smith, G., Taylor, M., Ashbaugh, J., Silver, J., & Heaviland, M. (2001). The Robert Wood Johnson Foundation Self-Determination Initiative:



Final Evaluation Report Abstract (2001). Available: <http://www.hsri.org/docs/767bRWJFEvalAb.PDF>

“In 1997, the Robert Wood Johnson Foundation invested in a broad range of demonstration activities around the country aimed at exploring the ways in which people with developmental disabilities can influence the character and configuration of the supports they receive through self-determination.” Nineteen state demonstrations were represented in the project. “While each local project was based on the same broad outline of values and objectives, there were significant differences given the variations in geography, socio-demographic factors, resources, service configuration, and economy.” The Human Services Research Institute of Massachusetts conducted an evaluation of this Self-Determination Initiative and summarized its findings in this report.” (Evaluation Report Abstract , p.1): <http://www.hsri.org/docs/767bRWJFEvalAb.PDF>)

## A. Critical Factors related to Self-Determination...

- “*Flexibility is Key*-the ability for funding systems to accommodate individual budgets and to expand the pool of contracted providers. Where systemic approaches to budget development (e.g., based on costs, and/or individual characteristics) were already in place (e.g., in Utah and Kansas), the task of making these individual resource allocations was facilitated” (Abstract-italics added, p.2).
- “The success of the self-determination initiatives in certain states had to do with the fact that leaders there *did not treat self-determination as a ‘project’ but rather embedded the approach throughout the system*” (Abstract-italics added, p.2).

Examples include: New Hampshire, Vermont, Dane and Winnebago Counties in Wisconsin-refer to citations below for more information).

- “Across the country, the ability to lead a self-determined life was significantly *influenced by the availability of direct support professionals*” (Full Report-italics added, p.6).
  - “Direct support staff did not always receive the level of training and orientation received by managers, executives, and other providers in person-centered and person-driven practice. In a decentralized system, direct support professionals play an absolutely crucial function and their role should be taken seriously by the system through increased compensation as well as training” (Full Report, p.7).
- “Leadership at the state and local level and the presence of innovation and momentum within a state were key elements in the success of the self-determination initiative...effective leadership to drive systems change must also include the actions of many” (Full Report, p.7-8).



**B. “Self-determination’s impact...**

- The juxtaposition of the self-determination demonstrations with the emerging aspirations of people with developmental disabilities combined to *spur the growth of organized self-advocacy*.
- The combination of person-centered planning and self-determination has sharpened the practice of person-centered planning in many states because it added *person-centered ‘doing’ to person-centered ‘thinking’*” (Abstract-italics not included, p.3).

**C. Exemplary States that embedded a self-determination approach throughout the system:****NEW HAMPSHIRE**

New Hampshire Project Summary: The Transition of New Hampshire’s Regional Service System: Creating Access to the Community Through Individually Determined Supports: Available: <http://www.unh.edu/rwj/states/nh.html>

**Contact:**

New Hampshire Department of Health and Human Services  
Division of Developmental Services  
State Office Park South  
105 Pleasant Street  
Concord, NH 03301  
Phone: (603) 271-5034/ (800) 852-3345; (800) 735-2964 (TDD)  
Fax: (603) 271-5166

**VERMONT**

Walker, P., Harris, P., Hall, M., Smith, V., & Shoultz, B. (November 2000). Self Determination in Vermont: Contributions of the Vermont Self-Determination Project. Available: <http://soeweb.syr.edu/thechp/Vermont.html>

Vermont Project Summary: Available: <http://www.unh.edu/rwj/states/Vermont.html>

**Contact:**

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the Center for Self Determination

Vermont Agency of Human Services:  
Office of the Secretary  
103 South Main Street  
Waterbury, Vermont 05671-0201  
(802) 241-2220



## WISCONSIN

Wisconsin Project Summary:

Available: <http://www.unh.edu/rwj/states/Wisconsin.html>

Further information is available by contacting Dennis Harkins at [dwharks@aol.com](mailto:dwharks@aol.com)

Dane County: <http://www.co.dane.wi.us/humanservices/acs/selfdirect.htm>

Winnebago County: Beth Culp: [BCulp@co.winnebago.wi.us](mailto:BCulp@co.winnebago.wi.us)

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## II. Person-Centered Supports-How Do States Make Them Work?

Bradley, V.J., Smith, G. Taub, S., & Heaviland, M. (November 2002). Person-Centered Supports-How Do States Make Them Work?

Available: <http://www.hsri.org/docs/793ESummary.DOC>

“[T]he ‘Reinventing Quality’ Project...[is] a collaborative undertaking of the National Association of State Directors of Developmental Disabilities Services (NASDDDS), The Human Services Research Institute (HSRI), and the Institute on Community Integration at the University of Minnesota (ICI/UM)... The fundamental aim of the Reinventing Quality Project is to support the efforts of state and local stakeholders of all types to accelerate the more widespread adoption of person-centered principles and practices in the operation of public systems serving people with developmental disabilities” (p.1). The Principles of Person-Centered Supports “are a comprehensive statement of the essential values that state systems must embrace so that all people with developmental disabilities are supported in realizing their own goals and aspirations for community life” (p.1). Four states (Connecticut, Kansas, Wisconsin, and Wyoming) were selected as exemplary.

### A. Shared characteristics of the four states “that contribute to their capacity to furnish person-centered supports”

- Financial support of persons with developmental disabilities “at an above average level of effort” (p.4)
- “Employing the HCBS Waiver program...to broaden access to community supports and offer individuals and families diverse services that could be tailored to their needs and preferences” (p.4)
- “[S]hared, well articulated values and a sense of mission” (p.4)
- “[C]ontinuity of leadership-not just at the top but throughout the system and at the provider level” (p.4)



- “Vigorous family support programs”(p.5)
- Creation of “solid quality assurance and improvement efforts” (p.5)
- “The Developmental Disabilities Councils, Protection and Advocacy agencies, and the University Centers for Excellence in Developmental Disabilities are valued partners and collaborators in reform” (p.5)
- “[A] relatively low case management ratio” (p.5)
- “[D]iversity and choice in case management (e.g., in Kansas, Wyoming, and Wisconsin, individuals increasingly have a choice of traditional or independent case managers)” (p.5)
- “[C]ommitment to person-centered planning and continual training in person-centered approaches.” (p.5)
- “[S]upportive of self-advocacy efforts, including enlisting self-advocates in system-level advisory capacities” (p.5)

## **B. “Implications for Other States”**

- “Hone person-centered planning skills through continuous training and indoctrination;
- Rethink and retool case management so that it is sufficiently funded and capable of guiding and assisting people toward person-centered supports;
- Sharpen the state’s vision through strategic planning and/or the enactment of reform legislation;
- Strengthen and support self-advocacy;
- Retool traditional quality assurance systems by putting the experience of the individual at the center of quality calculation;
- Take advantage of the flexibility of the HCBS waiver program to support the state’s vision of individual supports and expand access to services;
- Reach out to and collaborate with key stakeholders; and
- Implement quality improvement processes that analyze performance data and use such data to move toward increasingly person-centered practices” (p.9).

## **C. State Examples:**

### **CONNECTICUT**

“The purpose of this case study is to describe Connecticut’s journey toward a system that embraces the principles of person-centered supports.

In the early 1990s, policymakers in Connecticut began to take some intentional steps toward the ultimate goal of person-centered supports. One of the first steps was to make funds available for those on the waiting list more flexible and person-centered. This step paved the way for the entry of Connecticut into the Robert Wood Johnson Self Determination initiative and to the current move to Individual Support Agreements.

This case study report begins with a review of that recent history of system change and reform in Connecticut. This history explains how a state that had a relatively well-financed, albeit somewhat conventional system, began to unbundled its provider-driven system and to concentrate



policy and resources on individual choice and support. [They] then briefly describe how the Connecticut system is configured today...

People in Connecticut clearly understand that the principles of person-centered supports define the destination and they appear to be more than willing to take advantage of all opportunities including those presented by these difficult budget times, to further the cause of person-centered practice” (p. 6)

Quoted from the report: Bradley, V.J, Taub, S., & Smith, G. (December, 2002). Person-Centered Supports for People with Developmental Disabilities in the State of Connecticut. Available at: <http://www.hsri.org/docs/793DConnecticut.DOC>

## **KANSAS**

“The purpose of this case study is to describe Kansas’ journey toward a system that embraces the principles of person-centered supports. This journey began more than a decade ago when Kansans recognized that there was an enormous gulf between what people with developmental disabilities and families wanted and what the state’s service system had to offer. Throughout the 1990s, Kansans took bold steps to reform and reconfigure the service system so that people with developmental disabilities would “... be able to exercise options to choose where and with whom they live, where to work, to participate in preferred leisure activities, to be educated in schools in their neighborhoods and to build and maintain relationships with family friends.

Kansans mapped out an ambitious plan to extract the state from its over reliance on large congregate settings and build out community services squarely focused on supporting people with developmental disabilities and families in their communities. This plan was built on an especially strong foundation of person-centered principles. Starting with the Community Integration Project, a ‘person-centered culture’ was nurtured and took hold in Kansas. When one looks at the plan that Kansans crafted in the early 1990s and where the state’s service system stands today, one is struck by how faithfully Kansans stuck by their vision and how much of that vision came to pass.

This case study begins with recounting the history of system change and reform in Kansas. This history is especially interesting because system change in Kansas was not driven by litigation but instead by Kansans deciding for themselves that how people and families are supported had to be overhauled...The Kansas system as it is configured today is then briefly described” (p. 1)

Quoted from the report: Bradley, V.J., Smith, G., & Taub, S. (July, 2002). Person-Centered Supports for People with Developmental Disabilities in the Sunflower State. Available at: <http://www.hsri.org/docs/793CKansas.DOC>

## **WISCONSIN**

“Since the 1970s, Wisconsin has been a leader in embracing the principles of person-centered supports as the fundamental basis of publicly funded services for individuals with disabilities.” The Wisconsin visit “revealed that stakeholders remain fervently committed to the principles of person-centered supports. Those principles describe the fundamental expectations and vision for services and supports in Wisconsin. [They] saw continuing



evidence of the practicality and exciting outcomes that result when the principles are put into practice. There was no sense that the job is over or that Wisconsin can rest on its well-deserved laurels. However, it also was abundantly clear that the strategies that worked in the past to create community alternatives may not be the ones to guide the system to the next plateau. Moreover, Wisconsin faces many of the same challenges that other states face in order to solidify community services” (p. 2).

Quoted from the report: Bradley, V.J., Smith, G., & Heaviland, M. (2001). Wisconsin State Visit. Available at: <http://www.hsri.org/docs/793AWisconsin.DOC>

## WYOMING

“Over the past ten years, Wyoming has accomplished much in building out an especially strong network of community services and supports for its citizens with developmental disabilities. Wyoming today is vastly different than just ten years ago. All stakeholders have worked enormously hard to build a “system” that enables people with developmental disabilities to enjoy community life and provides meaningful support to families. By nearly any statistical measure, Wyoming stands out among the states as a leader in its commitment to its citizens with developmental disabilities. Wyoming has a positive and well-deserved reputation nationwide for its efforts to broaden opportunities for people to enjoy community life.

The selection of Wyoming for this case study relied on statistics and on Wyoming’s positive reputation. Statistics tell us (albeit imperfectly) that Wyoming has traveled far in its journey. Still, Wyoming people openly acknowledge that they have not reached their destination yet. There are more possibilities to explore and much more to learn.” (p. 1)

“Overall, Wyoming has a healthy and well-designed system that is headed in the right direction toward person-centered supports. The recent adjustments to its system architecture, in tandem with a more deliberate pursuit of person-centered principles, will likely accelerate the change process and make person-centered supports more pervasive throughout the state. The DOORS funding model provides a solid foundation for determining individual spending amounts. The administration is by nature open and responsive, and clearly supports efforts to inform and involve consumers and families. Based on our review of the Wyoming system and conversations with long-time advocates in the state, we would expect to see future growth in the areas of independent service provision, free choice of providers, authority of the planning team, and flexible use of Medicaid waiver funds.” (p. 37). (Please refer to the Waiver section of this promising practices report for more information on the DOORS program)

Quoted from the report: Smith, G., Taub, S., Heaviland, M., Bradley, V.J., & Cheek, M. (August, 2001). Making Person-Centered Supports a Reality in Wyoming: The Equality State’s Experience. Available at: <http://www.hsri.org/docs/793BWyoming.DOC>

### III. The Self-Determination Synthesis Project at the University of North Carolina at Charlotte (also Transition)

Wood, W.M. & Test, D.W. (2001). Final Performance Report: Self-Determination Synthesis Project. Available at: [http://www.uncc.edu/sdsp/final\\_report.pdf](http://www.uncc.edu/sdsp/final_report.pdf)



“The University of North Carolina at Charlotte...is conducting a review and synthesis of the knowledge base and best practices related to self-determination (SD) and self-advocacy (SA) interventions” (Quoted from website: <http://www.uncc.edu/sdsp/home.asp>).

“A comprehensive literature review and meta-analysis of [self-determination] outcomes was conducted...A series of qualitative case studies were conducted in six school districts across the country that had a demonstrated history of effectively promoting self-determination for their students. These districts primarily focused on self-determination for their transition-aged students... used a variety of strategies...[emphasized] [s]tudent participation in educational and transition planning...expected students (and to varying degrees, their parents) to take responsibility for working toward their goals and following through with the decisions required to meet those goals.” (Wood & Test, 2001, p. 1). “Common features across sites that contributed to self-determination outcomes for students included the presence of an impetus person, and multiple, changing roles of teachers and parents” (pp.1-2). “Present and past barriers included lack of administrative support, student-related factors, and the resistance of parents and professionals to changing roles” (p.2). The case studies include UIC Advocacy and Empowerment for Minority Youth with Disabilities Program: Empowering Choices Project (Chicago, Illinois) and the Monroe BOCES Circles of Support Program (Rochester, New York).

#### **A. Effective strategies and Recommendations when planning to implement self determination:**

- “*Begin earlier*”
- “*Parents and teachers need to agree about the course of self-determination instruction*”
- “*Teachers continue to need opportunities to learn how to effectively promote self-determination for their students*” (Wood & Test, 2001, p.15)

#### **B. Examples of Self-Determination Exemplar Sites:**

##### **1) Empowering Choices and Empowering Transitions Projects: Chicago, IL (also Transition)**

“The purpose of the Empowering Choices Project is to prepare youth (grades 11-12) with disabilities for competitive employment after graduating from high school. The goal of the Empowering Transitions Project is to develop students’ (grades 9-10) competencies to assume a proactive role in their education and vocational development. Both Projects emphasize goal setting and attainment, empowerment, and self-advocacy. The Projects also help students learn to recruit mentors who can help them achieve their personal goals. Both projects include a classroom-based curriculum and case management services. Empowering Choices emphasizes parent support and education, while Empowering Transitions emphasizes vocational guidance and exploration.”

*Exemplary self-determination practices:* 1) intensive case management 2) collaboration 3) parent education and 4) classroom-based curriculum



*What makes it work?*

- It is a program that has flexibility, because it is “based outside of the school system”...[and therefore,] “the Empowerment Projects are not as bound by district or building regulations”
- “Case managers emphasize trust building, confidentiality and acceptance”
- “Generalization of self-determination skills is built into the Projects”
- “Case managers model advocacy behaviors”
- “The approaches used by the Project staff are culturally competent”

The above information is quoted from the Self-Determination Synthesis Project website: (direct link: <http://www.uncc.edu/sdsp/uic.asp>)

## 2) Circles of Support BOCES #1 and Monroe 2- Orleans BOCES: Rochester, New York (also Education)

“The Circles of Support program began in 1998 with a grant from the New York Developmental Disabilities Council. The purpose of the project is to use person-centered planning to help families achieve desired outcomes for their transitioning students who have moderate and severe disabilities. Students, with their families, use MAPS to develop their goals, and then a Parent Partner helps families identify and access services to help students meet their goals. Parent Partners also link students with agencies and arrange job try-outs and other experiential opportunities so students can make informed choices about their future.”

*Exemplary self-determination practices:* 1) vocational try-outs and 2) person-centered planning

*What makes it work?*

- Creative staff that listen
- Agency representatives and parents attend to “behavioral indications of nonverbal students”
- Parent Partners [parents of a child with a disability] “educate the parents about the range of choices available to students and their families, so that they can make informed choices about services and supports”
- “Sharing a philosophy that is consistent with self-determination and choice for all students”

(The above information is quoted from the Self-Determination Synthesis Project website: (direct link: <http://www.uncc.edu/sdsp/boces.asp>)

## C. The Self-Determination Synthesis Project Website:

<http://www.uncc.edu/sdsp/home.asp> includes:

- a.) Self-Determination Technical Assistance Centers (SDTAC)
- b.) Transition Technical Assistance Centers (TTAC)
- c.) Self-Advocacy Synthesis Project



Self-Determination Synthesis Project  
David Test, Project Contact  
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Website: <http://www.uncc.edu/sdsp>

## **ADDITIONAL RESOURCES:**

### **Beach Center on Disability at the University of Kansas:**

Haworth Hall  
1200 Sunnyside Avenue, Room 3136  
Lawrence, KS 66045-7534  
Phone: (785) 864-7600  
Fax: (785) 864-7605  
TTY: 785-864-3434  
Email: [beachcenter@ku.edu](mailto:beachcenter@ku.edu)  
Website: <http://www.beachcenter.org>

The Beach Center offers resources and seeks to:

- “A. Improve the quality of life of individuals with disabilities, their family members, professionals who serve them, and members of the communities where the individuals and families live.
- B. Use quality of life as a desired outcome and originating principle for our work and as the primary basis for making decisions about projects and their products.
- C. Promote the structuring of policy and the delivery of services with a view toward inclusive communities.
- D. Address the challenges facing our constituents from two perspectives: (1) the individual constituent and/or (2) the policy and service systems with which the constituent is involved.
- E. Create partnerships (characterized by commitment and readiness and operationalized within KU and with our external colleagues) in research, training, teaching, technical assistance, and product development with our constituents.
- F. Use both ethics and data in decision-making.”

The above information is quoted from the Beach Center Website (direct link: <http://www.beachcenter.org/default.asp?act=aboutus&section=affiliation>)

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### **Center on Self-Determination at the Oregon Institute on Disability and Development:**

Oregon Institute on Disability and Development  
Child Development and Rehabilitation Center  
Oregon Health and Science University  
707 SW Gaines Road  
Portland, Oregon 97239  
Phone: (503) 494-8364  
Website: <http://www.selfdeterminationohsu.org/>

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“The Center on Self-Determination identifies, develops, and shares approaches that promote the self-determination of people with disabilities and ongoing health conditions. The Center is staffed by experts in disability and health issues, research and training. [They] work closely with consumer groups, organizations, schools and agencies to develop model programs and public policies that support self-determination. [They] also produce materials and conduct training for professionals and community organizations.”

The above information is quoted from the Center on Self-Determination website  
(direct link: <http://www.selfdeterminationohsu.org/>)

### **The Center for Self-Determination**

Main Office  
401 East Stadium Boulevard  
Ann Arbor, MI 48104  
Voice: (734) 213-5220  
Website: <http://www.self-determination.com>  
On this website you can search for self-determination activities by state



## TRANSITION TO ADULTHOOD

“On December 3, 2004, President George W. Bush signed H.R. 1350 (IDEA 2004) into law”

According to H.R. 1350 (IDEA 2004), “TRANSITION SERVICES” are defined as “a coordinated set of activities for a child with a disability that—

(A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(B) is based on the individual child’s needs, taking into account the child’s strengths, preferences and interests; and

(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.”

(The above information is quoted from the NCSET website; bold formatting removed ; direct link: <http://www.ncset.org/publications/related/ideatransition.asp>)

Note: “Most provisions of the new law take effect on July 5, 2005”

(Quoted from the Wrightslaw website; direct link: <http://www.wrightslaw.com/idea/index.htm>)

To see how the definition of transition services is defined in IDEA 1997 as compared to H.R. 1350 (IDEA 2004) visit the NCSET Website: <http://www.ncset.org/publications/related/ideatransition.asp>

### I. A BROAD OVERVIEW OF TRANSITION TO ADULTHOOD THROUGH REPORTS

**A. The United States General Accounting Office (GAO) (July 2003). Report to the Ranking Minority Member, Committee on Health, Education, Labor and Pensions, U.S. Senate. Special Education: Federal Actions Can Assist States in Improving Postsecondary Outcomes for Youth. (GAO-03-773). Washington, DC: Author. Available at: <http://www.gao.gov/new.items/d03773.pdf>**

The report from the U.S. General Accounting Office (GAO) makes “recommendations to [the Department of] Education to help state and local education agencies improve transition outcomes for IDEA youth by disseminating information on best practices for collecting and using data on their postsecondary status, providing more timely and consistent services to states seeking assistance, and identifying strategies for informing students and families about federal transition resources” (Quoted from GAO (July, 2003), p.5 available: <http://www.gao.gov/new.items/d03773.pdf>).



**B. National Center on Secondary Education and Transition (NCSET) (2003). A National Leadership Summit on Improving Results for Youth: State Priorities and Needs for Assistance. A September 2003 Summit hosted by NCSET in Washington, DC. Available: <http://www.ncset.org/summit03/findings.htm> (click on link for *Download Findings & Outcomes in PDF*)**

“In response to the need to improve secondary education and postschool outcomes for youth with disabilities, NCSET hosted, in September 2003, its first *National Leadership Summit on Improving Results for Youth*. More than 250 state agency leaders, policymakers, and professionals representing general education, special education, career and technical education, workforce development, vocational rehabilitation, and other agencies participated... The purpose of the two-day event was to build state capacity to develop more results-driven state systems so that youth with disabilities achieve more desirable postschool outcomes” (p.2).

“The priority issues that emerged from states in attendance at the National Leadership Summit are consistent with those identified in various national sources. States continue to stress the importance of *developing collaborative relationships and aligning special programs with broader education and workforce reforms* so that all youth have the opportunity to achieve successful academic, occupational, and social outcomes. These priorities also revealed *strong concerns from state leaders about collecting, reporting, and using outcome data to improve services and programs*. Moreover, *the education and involvement of youth and families in the transition planning process remains a critical need.*” (P. 5, italics added)

(The above quotes are from NCSET (2003). A National Leadership Summit on Improving Results for Youth: State Priorities and Needs for Assistance. A September 2003 Summit hosted by NCSET in Washington, DC. Available: <http://www.ncset.org/summit03/findings.htm> (click on link for *Download Findings & Outcomes in PDF*).

**C. The National Council on Disability (November 1, 2000). Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Post-Secondary Education and Employment. Washington DC: Author. Available: [http://www.ncd.gov/newsroom/publications/2000/transition\\_11-01-00.htm](http://www.ncd.gov/newsroom/publications/2000/transition_11-01-00.htm)**

The “report presents an analysis of research on the status of transition, post-secondary education, and employment outcomes for primarily 14 to 22 year old youth and young adults with disabilities over the past 25 years. Next it identifies what has worked, and what should work in light of unmet needs and unserved populations. Finally, the report presents recommendations for national, state, and local community action” (p. 3/33 online version) “Overall, NCD’s recommendations for action at the state, local, and community level underscore the *need to remove administrative disincentives for collaboration and coordination of efforts, document and share information about what works, including integration of preparation for transition into daily school life and greater involvement of community resources at all levels, and innovation in ways of reaching diverse cultures, underserved and unserved populations*” (p. 6/33 online version, italics added). The NCD report includes a list of nine “Recommendations to State, Local, and Community Entities” in the end.



(The above information is quoted from The National Council on Disability (November 1, 2000). Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Post-Secondary Education and Employment. Washington, DC: Author. Available: [http://www.ncd.gov/newsroom/publications/2000/transition\\_11-01-00.htm](http://www.ncd.gov/newsroom/publications/2000/transition_11-01-00.htm))

## II. RESEARCH

### **A. The ERIC/OSEP Special Project. News Brief: Six Strategies Make Model Transition Programs Excel.**

**Available:** <http://ericec.org/osep/newsbriefs/news9.html>. This brief is based on the research of Susan Brody Hasazi, Katherine S. Furney, and Lizanne DeStephano, (Summer, 1999).

“Implementing the IDEA transition mandates.” *Exceptional Children*, 65(4) 555-566.

“Researchers at the University of Vermont and the University of Illinois have conducted a qualitative study of factors that support the success of school districts’ transition programs. The study...used a panel of national experts to identify five sites that had model transition programs and four sites that represented typical transition programs. Interviews, observations and document reviews were conducted at each site and cross-case analysis was performed.

Results suggested several differences between the model and representative sites: Model sites showed more indicators of support for implementing transition planning and services, and the *use of promising practices was more widespread and systematic than in the representative sites*” (italics added).

“The model sites incorporated six factors”

- o “Systemwide student- and family-centered strategies”
- o “Effective and substantive interagency collaboration”
- o “Systematic professional development”
- o “Visionary, supportive and inclusive leadership”
- o “Integrated educational reform”
- o “Connected local and federal initiatives”

(The above information is quoted from: The ERIC/OSEP Special Project. News brief: Six Strategies Make Model Transition Programs Excel. Available: <http://ericec.org/osep/newsbriefs/news9.html>)

### **B. The ERIC/OSEP Special Project. News Brief: Action Needed to Address Current Challenges Facing Transition.**

**Available:** <http://ericec.org/osep/newsbriefs/news31.html>

This brief is based on the research of David R. Johnson, Robert A. Stodden, Martha L. Thurlow, Ellen J. Emmanuel, Richard Luecking, and Mary Mack. (Summer 2002). “Current Challenges Facing Secondary Education and Training Services for Youth with Disabilities: What Research Tells Us.” *Exceptional Children*, 68(4).



“Researchers have identified five areas in which improvements in secondary transition services will benefit special education students, accompanied by strategies that can be used to bring about these improvements...”

- o Ensuring that students with disabilities have access to the full range of general education curricular options and learning experiences
- o Making high school graduation decisions based on meaningful indicators of students’ learning and skills and clarifying the implications of different diploma options
- o Ensuring access to and full participation in postsecondary education, employment, and independent living
- o Further increasing student and family participation in discussion and decision making
- o Improving collaboration and coordination between educational and other agencies at the federal, state, and local levels”

(The above information is quoted from The Eric/OSEP Special Project. News Brief: Action Needed to Address Current Challenges Facing Transition. Available: <http://ericec.org/osep/newsbriefs/news31.html>)

### **III. EXAMPLES**

#### **NATIONAL**

##### **1) Institute on Community Integration (UCEDD), University of Minnesota:** <http://ici.umn.edu/>

Their “mission is to improve the community services and social supports available to individuals with developmental and other disabilities, and their families, throughout the United States and abroad. [They] fulfill this mission through research, professional training, technical assistance, and publishing activities” (Quoted from the Institute on Community Integration website: <http://ici.umn.edu/>).

##### **Transition Services Program Area:**

“The Transition Services Program Area works to enable schools and community service agencies to better prepare youth with disabilities for life as productive, responsible adults in the community. This goal is pursued through the evaluation of post-school outcomes for students with disabilities, implementing models of collaborative transition planning and service delivery, providing technical assistance to state and local educational and vocational rehabilitation programs, promoting meaningful policy development and systems change in supporting youth with disabilities and families in the transition from school to adult life, generating and evaluating strategies for successful community employment for persons with disabilities, and preservice and continuing education of professionals and parents.” (Quoted from the Institute on Community Integration website (direct link to the Transition Program Area: <http://ici.umn.edu/projectscenters/transition.html>).

Institute on Community Integration  
University of Minnesota  
102 Pattee Hall, 150 Pillsbury Drive SE  
Minneapolis, MN 55455  
Phone: (612) 624-6300; Fax: (612) 624-9344



**a) National Center on Secondary Education and Transition (NCSET)**

“(an ICI Affiliated Center) provides technical assistance and information dissemination on improved access and success for students with disabilities in secondary and postsecondary education, as well as employment, independent living, and community participation. It is a collaboration with the Center on Disability Studies, University of Hawai’i, Manoa; TransCen, Inc.; the Institute for Educational Leadership’s Center for Workforce Development; PACER Center; and the National Association of State Directors of Special Education. Funded by U.S. Department of Education, Office of Special Education and Rehabilitative Services. Contact: David R. Johnson, 612-624-2097, [ncset@umn.edu](mailto:ncset@umn.edu).” (Quoted from the Institute on Community Integration Website; direct link: <http://ici.umn.edu/projectscenters/transition.html>).

National Center on Secondary Education and Transition (NCSET)

Institute on Community Integration

University of Minnesota

6 Pattee Hall, 150 Pillsbury Drive SE

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Contact:

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Additional promising practices include:

- ☐ vocational and community use training (Iowa)
- ☐ centers for independent living and transition (Kansas)
- ☐ self-determination and transition (Kansas)
- ☐ professional development (Kansas)
- ☐ inclusive post-secondary education (Virginia)
- ☐ computer and networking technologies – “DO-IT” (Washington)



**IOWA (also Education)****Vocational and Community Use Training**

“Our program utilizes strategies that assist in providing age-appropriate, life skills training activities that allow individuals to achieve greater independence.

In our classrooms we assist persons in improving their skills in vocational, recreational, and community use activities. (Some examples are... making and keeping appointments, using personal or public transportation, using community facilities and services, using a telephone, laws/rules, interpersonal relationships, shopping, banking, pedestrian safety...).

This is accomplished in the classroom using activities that assist individuals in gaining knowledge needed to increase independence. A wide range of instructional techniques is utilized in maximizing performance using small group and individualized instruction to develop and improve skills that meet individual program plans.” <http://www.niacc.cc.ia.us/progserv/learningsupport/disabilities.html>

Contact:

[request@niacc.edu](mailto:request@niacc.edu)

641-423-1264 or

1-888-GO NIACC

500 College Drive

Mason City, Iowa 50401

**KANSAS/NEW YORK****Kansas University Center on Developmental Disabilities (KUCDD)****“The Role of Centers for Independent Living in the Transition of Youth with Developmental Disabilities” (also Transition)**

(NIRS database description of the project: [http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=579&keywords=self52Ddetermination%20and%20transition](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=579&keywords=self52Ddetermination%20and%20transition))

The Rehabilitation Research and Training Center on Independent Living Management (RRTC-ILM) of Western New York is collaborating with the Beach Center on Disability at the University of Kansas in youth transition to identify “the best practices and [develop] test programs for [Centers for Independent Living (CILs)], to expand their services to youth with disabilities and their families.”

The goals of the project are:

- “to analyze the full range of literature pertaining to best practices in services for youth with disabilities and their families
- to identify promising field-based models of CILs serving youth with disabilities and their families
- replicate these best practices from other fields and reconcile them with promising practices within the CILs



- conduct training and disseminate information about the potential and actual role of CILs in the transition process.”

(The above information is quoted from the RRTC-ILM Website; direct link: <http://www.wnyilp.org/RRTCILM/progress.html>)

The Rehabilitation Research and Training Center on Independent Living Management (RRTC-ILM):  
<http://www.wnyilp.org/RRTCILM/progress.html>

The Western New York Independent Living Project, Inc.

3108 Main Street

Buffalo, NY 14214

(716) 836-0822 (Voice and TDD); (716) 835-3967 (Fax)

Contact: [info@wnyilp.org](mailto:info@wnyilp.org)

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## KANSAS/OREGON

### **“self-determination in transition to Adulthood for Youth with Disabilities: The Impact of interventions on self-determination and Adult Outcomes” (also Transition)**

(Description Available on the NIRS Database (Direct Link: [http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=4444&keywords=self%2Ddetermination%20in%20transition](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=4444&keywords=self%2Ddetermination%20in%20transition))

*“Promoting and enhancing the self-determination of youth with disabilities has become [a] best practice in transition services. However, despite the wide visibility of the importance of self-determination to achieve positive life outcomes for youth with disabilities, there is very little research to document both the capacity of interventions designed to promote such outcomes to actually do so and of the impact of such interventions (and enhanced self-determination) on outcomes for youth. Researchers at The Kansas University Center on Developmental Disabilities and the Beach Center on Disability, both at the University of Kansas, and the Center on Self-Determination at the Oregon Health Sciences University propose to conduct a project under the NIDRR Disability Rehabilitation Research Projects (DRRP) competition on ‘Research Projects for Stabilizing and Improving Lives of Persons with Disabilities,’ priority (a) ‘self-determination in transition to Adulthood for Youth with Disabilities’ to address this gap in the knowledge base. The proposed project will conduct three semi-longitudinal, national research studies examining the impact of interventions to promote the self-determination of students with high incidence... and low*



incidence disabilities...and students who are at-risk for poor adult outcomes...on student self-determination and on the impact of self-determination on adult outcomes and quality of life” (italics added).

(The above information is quoted from the NIRS Database; direct Link: [http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=4444&keywords=self%2Ddetermination%20in%20transition](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=4444&keywords=self%2Ddetermination%20in%20transition))

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Email: [wehmeyer@ku.edu](mailto:wehmeyer@ku.edu)

## KANSAS

### **“Beyond High School: Infusing Self-Determination into 18-21 Services for Students with Mental Retardation”**

“The Plano Independent School District (PISD) and KUCDD/Beach Center on Disability at the University of Kansas are conducting a project to develop, implement, evaluate, and nationally disseminate a model for the education of students with mental retardation ages 18 – 21 which incorporates components of best practice in the education of students with mental retardation and overlays on this framework innovative procedures to promote self-determination. The project utilizes the capacity of the PISD’s Fullstream program to provide quality services to students with mental retardation ages 18 – 21, the capacity of the Beach Center’s projects on self-determination to develop replicable model programs to promote student self-determination, and the capacity of the Beach Center, a NIDRR-funded Rehabilitation Research and Training Center, to disseminate project findings to a national audience.”

(The above information is quoted from the NIRS Database; direct link:

[http://www.aucd.org/nirs/db/search/prj\\_view.cfm?id=4140&keywords=self%2Ddetermination%20and%20transition](http://www.aucd.org/nirs/db/search/prj_view.cfm?id=4140&keywords=self%2Ddetermination%20and%20transition))

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## **KANSAS**

### **Transition Coalition**

“The mission of the Transition Coalition is to maximize professional development in secondary school reform and transition at the national, state, and local levels. The Coalition supports best practices and creates professional development forums using face-to-face and online training and technical assistance.” <http://www.transitioncoalition.org/aboutus.php3>

The Transition Coalition provides online training, personal development and staff development activities and a week long summer transition institute. “The Summer Transition Institute is geared toward professionals and family members involved with secondary transition programs and services for students with disabilities. The Transition Institute provides some overview information for those new to transition services but primarily provides updated information on recommended practices in interprofessional transition education and services for current professionals and parents.” <http://www.transitioncoalition.org/institute/index.html>

Contact:  
Transition Coalition  
University of Kansas  
Department of Special Education  
Joseph R. Pearson Hall  
1122 West Campus Rd., Room 521  
Lawrence, KS 66045-3101  
785-864-0686 voice

## **VIRGINIA (also Education)**

### **George Mason Learning Into Future Environments (L.I.F.E.) postsecondary program**

“The GMU LIFE Program is an innovative, inclusive postsecondary program for young adults with intellectual disabilities who want to experience college life in a supportive environment.

The GMU LIFE Program has two complementary missions:

- To provide young adults, whose disabilities have traditionally excluded them from higher education, with an inclusive university experience that will further their literacy skills and prepare them for employment and independent living in their communities.
- To provide GMU students who are majoring in disciplines such as education, psychology, assistive technology, social work, etc. with practical experience learning from and working with, individuals with disabilities.



The Program has three Primary Goals:

- Increase Literacy Skills: Reading, Writing, Math, Technology.
- Expand career development, exploration, and employment experiences and options.
- Increase independent living skills and access to community opportunities.

The GMU LIFE Program is designed to be a four to six year program (depending on a student's needs and age). A sample program sequence for a student might be:

**Years 1-2:** The student attends classes during the day from 9:00 AM to 3:00 PM, Monday through Friday.

**Years 3-4:** The student may have the option to reside in a residence hall on campus from Sunday through Thursday while attending classes Monday through Friday. (note: the residence hall component is intended to be available beginning the 2005-06 academic year, and will entail additional fees).

**Years 5-6:** The student will ideally be employed, live with family or as independently as possible in the community, and may attend classes in the evenings.

Students are admitted to the GMU LIFE Program between the ages of 18-22, however students may only remain in the program through the year in which they turn 25.” <http://www.kihd.gmu.edu/gmulife/#mission>

Contact:

Clare Talbert, Program Director

Patti Lindstrom, Program Coordinator

703-993-3670

GMULIFE@gmu.edu

## **WASHINGTON**

### **Disabilities, Opportunities, Internetworking, and Technology**

“Many capable individuals with disabilities face challenges as they pursue academics and careers. They are underrepresented in many rewarding career fields, including science, engineering, business, and technology. DO-IT (Disabilities, Opportunities, Internetworking, and Technology) serves to increase the participation of individuals with disabilities in challenging academic programs and careers. It promotes the use of computer and networking technologies to increase independence, productivity, and participation in education and employment.

DO-IT has received national and regional awards including the National Information Infrastructure Award in Education; the King County Adult Service Agency Award, an Outstanding Program Award from the Washington Association on Post Secondary Education Disability (WAPED); the HealthyWay Best of the Web Award; and the President's Award for Excellence in Science, Mathematics, and Engineering Mentoring of underrepresented groups. DO-IT was also showcased in the 1997 President's Summit on Volunteerism and the 1996 NSF Dynamic Partnerships invitational conference.”



The DO-IT team consists of:

**“DO-IT Scholars** are college-capable high school students with disabilities who have leadership potential. DO-IT Scholars are loaned computers, software, and adaptive technology for use in their homes. They use the Internet to access information and to communicate with others. DO-IT Scholars gain academic, career, and personal insights by communicating electronically with each other and with DO-IT Mentors. They attend live-in summer study programs at the University of Washington and participate in work-based learning experiences.

**DO-IT Pals** are teens with disabilities who participate in an electronic community to support their academic and career goals. They provide their own computer systems and Internet access, usually through their homes, schools, or libraries.

**DO-IT Ambassadors** are DO-IT Scholar high school graduates who continue to support DO-IT efforts, participate in the electronic community and work-based learning experiences, and mentor younger Scholars and Pals.

**DO-IT Campers** are participants in selected summer camps for children and youth with disabilities. DO-IT staff travel to these camps to teach Internet, college, and career transition skills.

**DO-IT Mentors** include college students, faculty, and professionals in a wide variety of career fields. Many have disabilities themselves. Mentors help DO-IT participants succeed in college and employment as they communicate via electronic mail and during program activities.

**DO-IT Staff, Interns, and Volunteers** coordinate programs, electronic communications, research, and dissemination.” <http://www.washington.edu/doit/Brochures/overview.html>

Contact:

Sheryl Burgstahler

206-685-DOIT (3648)

[sherylb@u.washington.edu](mailto:sherylb@u.washington.edu)

## ADDITIONAL RESOURCES

### What Works Transition Research Synthesis Project

“The *What Works* Transition Research Synthesis Project is a new project funded by the Office of Special Education Programs (OSEP) to review and synthesize the past 20 years of research and advancements in the area of transition for youth with disabilities. [They] are a group of researchers, educators, parents, and practitioners from Colorado State University, working with a national advisory board comprised of experts from around the country who are also experts in the field. [The] project office is located in the School of Education at Colorado State University.”

“The *What Works* Transition Research Synthesis Project is organized around these project goals:

1. To produce four research syntheses [“academic outcomes,” “dropout prevention,” “transition outcomes,” and “other voices from the field”] of *empirical* transition literature;
2. To produce one research synthesis of *non-empirical* transition literature; and
3. To proactively disseminate all written products and sustain the activities of the project.”



(The above information is quoted from the What Works Data Brief (Volume 1, Issue 1) (December 2002): A report from the What Works Transition Research Synthesis Project on the National Center on Secondary Education and Transition Website (NCSET). Available: <http://www.ncset.org/publications/viewdesc.asp?id=714>

Contact

Brian Cobb

970-491-6835

[cobb@cahs.colostate.edu](mailto:cobb@cahs.colostate.edu))

Morgen Alwell

Colorado State University

970-491-6284

[alwell@cahs.colostate.edu](mailto:alwell@cahs.colostate.edu)

**The Virginia Department of Education's Transition Services website**

**Contains a section with links for best practices from around the Country:**

<http://www.pen.k12.va.us/VDOE/sped/transition/bpit.shtml>



## **TRANSPORTATION**

The DD Act of 2000 states that “individuals with developmental disabilities need to have access to and use of public transportation, in order to be independent and directly contribute to and participate in all facets of community life...The term “transportation-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of transportation.”

Promising practices include:

- ☐ Reimbursement for volunteer drivers (California)
- ☐ Smart transportation using GPS technology (Colorado)
- ☐ Rural transportation initiatives (New Hampshire)
- ☐ Tool to assess if voucher program is appropriate for community (North Dakota)
- ☐ Training for taxi drivers (Tennessee)
- ☐ Accessible Community Transportation (Rhode Island)
- ☐ Collaborations between multiple agencies to fill transportation routes (Virginia)
- ☐ Contactless smart cards (Virginia)
- ☐ State legislation (Washington)
- ☐ Bus familiarization training (National)

## **CALIFORNIA**

### **Partnership to Preserve Independent Living**

“Finding informal providers can save money and improve services. In Riverside County, California, just east of Los Angeles, the Transportation Reimbursement and Information Project (TRIP) complements public transportation by reimbursing volunteers to transport individuals where no public transportation service exists or when an individual is too frail to use other transportation. Public transportation services would cost at least \$1.5 million more than the transportation services provided by TRIP” <http://www.fta.dot.gov/CCAM/Intro.pdf>

“Information on public transportation, everywhere in Riverside County, is also provided through a single toll-free phone call to the Riverside County Office on Aging HelpLink at 1-800-510-2020. HelpLink’s Services Specialists discuss transportation needs with callers, make referrals to providers who can assist them, send out brochures, route schedules, and referral to the American Disabilities



Act certification process of transit agencies, if appropriate” <http://www.livingpartnership.org/Transportation.htm>

Contact:

[executivedirector@livingpartnership.org](mailto:executivedirector@livingpartnership.org)

[richard.smith@pe.net](mailto:richard.smith@pe.net)

Partnership to Preserve Independent Living

6296 Rivercrest Drive, Suite K

Riverside, CA 92507-0738

951-697-4697

## COLORADO

<http://l3d.cs.colorado.edu/clever/projects/mobility.html>

“The Mobility-for-All project is exploring mobile technologies and architectures that lower barriers to community access and independence for persons with cognitive disabilities. [They] are collaborating with disability communities, urban planners, innovative technology companies, and transportation system designers to understand and address problems faced by travelers with cognitive disabilities and their caregiver communities.”

“[Their] research has resulted in a technical architecture and prototype components that leverage Global Positioning System (GPS) technologies now being introduced to manage bus fleets in major US cities. The Mobility-for-All architecture:

- provides mobile, contextualized, personalized, “just in time,” multi-modal (visual, auditory, or tactile) prompts;
- reduces cognitive loads by focusing memory and attention on critical tasks including which bus to board, when to get off, and where to go next -much like caregivers do as they train new users;
- communicate special user needs (e.g. a destination or needed connections; physical access needs; etc.) to system operators so bus system operators can provide assistance; and
- allows caregivers or family members to monitor trip progress, detect errors, and offer assistance - while maintaining privacy. <http://l3d.cs.colorado.edu/clever/assets/flyer/mfa.pdf>

Contact:

Jim Sullivan, PhD

Co-Director, Cognitive Levers Project

Center for LifeLong Learning and Design

Department of Computer Science

University of Colorado at Boulder

<http://www.cs.colorado.edu/~l3d/clever>

[sullivan@cs.colorado.edu](mailto:sullivan@cs.colorado.edu)



## NEW HAMPSHIRE

### Rural Transportation Access Network Project

<http://iod.unh.edu/RTAN/>

“A two-year grant recently awarded to the Institute on Disability at the University of New Hampshire will address important issues that people with disabilities and others who may not drive in this society struggle with everyday: Access to practical and affordable transportation in less-populated areas. Rural transportation access in the state and the country is limited and has a significant impact on the ability of people who do not or choose not to drive to participate in community life, go to places of employment, attend educational opportunities, and visit friends and families - activities that drivers take for granted.”

“The Rural Transportation Access Network Project (RTAN) is a two-year, \$100,000 grant awarded to the Institute on Disability at UNH by the U.S. Department of Health and Human Services’ Administration on Developmental Disabilities. The project seeks to:

- Identify and evaluate best practices in inclusive rural transportation
- Collect and compile data about the impact of barriers to transportation access on persons with disabilities and their communities
- Develop Web-based materials to share best practices in rural transportation
- Identify and disseminate funding resources and practices to develop and maintain transportation opportunities in rural communities
- Organize and host a national summit on transportation for individuals with developmental disabilities residing in rural communities

“RTAN will also identify strategies to increase and coordinate existing services, funding resources and gaps in funding structures and policies. It is anticipated that the project will produce recommendations for policy changes, model practices and model organizational structures” (<http://iod.unh.edu/projects/RTAN.html>)

Contact:

Sönke Dornblut

[sonke.dornblut@unh.edu](mailto:sonke.dornblut@unh.edu)

## NORTH DAKOTA

### Grit Voucher System and Online Assessment

“A voucher system is a method of payment that enables people with disabilities living in rural communities to obtain and afford transportation. A voucher system enables the person with a disability to reimburse neighbors, friends, providers who accept vouchers and in some cases relatives (if allowed under state law) for rides.”

“Federal, state or local agencies that fund rural transportation (i.e. Department of Transportation, Medicaid, Vocational Rehabilitation) develop a “purchase of service agreement” with a voucher site



or broker. The person with a disability decides where he or she wants to go and finds a driver with a vehicle who can provide a ride. The consumer may use a rural transportation provider (as long as the provider agrees to accept and reimburse the voucher) or a neighbor, friend, relative or family member (if reimbursable by the funding source). The individual pays the driver with the voucher. The driver sends the voucher to a GRIT site along with the necessary documentation of the ride. The type of documentation required by the funding source (i.e. destination, mileage, etc.) is printed on the voucher. Other special forms required by the funding source may be handled by some voucher sites as well. The driver is reimbursed by the voucher site at an agreed-upon rate. The voucher site then submits the voucher and documentation to the funding source and maintains any necessary records. The funding source reimburses the voucher site at an agreed-upon rate. The funding source can audit the voucher site.” <http://ndcpd.misu.nodak.edu/grit/caodefine.html>

An online assessment tool is available for communities to determine if a voucher system is appropriate for them <http://ndcpd.misu.nodak.edu/grit/CAOwelcome.html>

Contact:

Cathy Haarstad

[Cathy.Haarstad@minotstateu.edu](mailto:Cathy.Haarstad@minotstateu.edu)

## **RHODE ISLAND (also Funding, Employment, Self-Determination)**

### **Accessible Community Transportation**

“...After Mark maps out a route for a client, he and Terri, his business support associate, travel **with** the client along the route for as many times as it takes the client to learn. Then they test the client by having him or her take the trip alone, with Mark and Terri following at a distance. Mark’s clients find it especially helpful that he is a professional travel trainer who also has a disability.”

“The Rehabilitation Services Department (VR) and the Developmental Disabilities Department funded Mark to get services from a supported employment provider, but the support staff were unreliable. Mark wanted **one** person who believed in his work to be his business associate. Mark’s dad knew about flexible funding through his work at a disability organization, and he realized that it could be useful to Mark.”

“There wasn’t a real program of flexible funding for employment services at the Developmental Disabilities Department, ... Mark’s proposal would allow Mark to hire just one person to help him with both business and household and personal tasks. Some of his support person’s salary would come directly from earnings from the business. The Developmental Disabilities department approved the plan, and Mark was given the funding to implement it. He hired Terri.”

“Now she is his director of business operations, helping with the billing and other paperwork. Mark and Terri plan the travel training routes for the clients and then go out and train them. She is a true business partner, working with Mark even at 5:00 in the morning when they need to train someone to reach an early morning job. And as planned, Terri also does things like make lunch. Mark signs Terri’s timesheets so that she can be paid by an agency that handles the payroll. This has worked smoothly.”



“So far, Mark works mostly as a vendor to VR. The contract he and his family developed also allows him to work on a fee-for-service basis for other places, such as a school that had a student who needed to learn to travel independently. Between August 1998 and October 2002, he trained 30 people.”

“Mark is well known as a transportation authority in his state, and serves on state advisory boards. Accessible Transportation Advisory Committee and Disability Services Improvement Subcommittee. He also gives speeches at local high schools. He is a member of his local Chamber of Commerce. Mark has future plans for his business. Eventually, he would like to sell his travel training services to other state agencies. Recently he has incorporated his business, Accessing Community Transportation (ACT), Inc., as a not-for-profit corporation. He wants the business to grow so that he can earn a steady income even when he doesn’t have one-on-one travel training clients. He is interested in training department staff about public transportation for people with disabilities, and possibly serving as a consultant for the Tourism Bureau. The possibilities are limitless!” [http://www.communityinclusion.org/publications/flex\\_funding/index.php?page=mark](http://www.communityinclusion.org/publications/flex_funding/index.php?page=mark)

Contact:  
Mark Susa  
401-461-5494

## TENNESSEE

“The Center for Independent Living of Middle Tennessee (CILMT) has partnered with the Nashville Convention and Visitor’s Bureau to provide an hour of training on serving customers with disabilities to the over 400 cab drivers in Nashville. Taxi cab drivers in Nashville are required to undergo this annual two-hour training in order to retain their permits.”

“To conduct part of the training, a panel consisting of CILMT staff, a representative from the Epilepsy Foundation, a person using a power wheelchair, a person who alternates between the use of crutches and a manual wheelchair, and a representative from Tennessee Protection & Advocacy who is blind and uses a service animal. Each panelist covers a portion of the training and supplements the discussion with description of their own experiences. Drivers are encouraged to ask questions of each speaker.” <http://www.cil-mt.org/index9.html>

Contact:  
[cilmt@tndisability.org](mailto:cilmt@tndisability.org)  
Center for Independent Living of Middle Tennessee  
480 Craighead Street, Suite 200  
Nashville, TN 37204  
615-292-5803



## VIRGINIA

“In the Northern Shenandoah Valley of Virginia, the human service agencies came together three years ago seeking ways to improve their transportation services in a cost effective manner that acknowledges the unique populations they serve and the requirements of the agencies.

The Northern Shenandoah Valley Public Mobility Program is currently developing an Operational Test for the coordination system the Program has deployed. The system provides a networked computer aided dispatching system to coordinate and integrate the transportation services provided by the human service agencies. The dispatching system will provide the means for the agencies to coordinate their transportation services, enhance the number of vehicles and seats available for their clients and, provide demand-responsive and flex-routing resources.

- The Public Mobility Program will employ a contactless smart card.
  - The system users ...may have mental or physical disabilities that limit their physical or cognitive ability to manipulate a card that requires either swiping through or insertion into a slot.
- The Public Mobility Program will employ a Mobile Data Terminal for the smartcard.
- The Mobile Data Terminal will:
  - Have the capacity to ‘read’ the client information from the smart card, relate the client information to the vehicle manifest, confirm the trip and trip segments and display the verified information to the driver.
  - The MDT will have the capacity to access client special needs information and display the information to the driver.
  - The MDT will have the capacity to access client emergency contact information and display the information to the driver.
  - The MDT will have the capacity to access and verify driver information.
  - The MDT will have the capacity to access and display in map and tabular format the vehicle’s trip manifest.
- The Mobile Data Terminal will incorporate Automatic Vehicle Location for:
  - Routing
    - The MDT/AVL system will display real time vehicle location information for the driver for emergency notification and response.
    - The MDT/AVL system will provide and display vehicle routing information for scheduled and unscheduled trips.
  - The AVL technology will provide vehicle location for emergency response.
    - The AVL technology will provide vehicle tracking for flex-routing and demand responsive services.
    - The AVL technology will be employed to provide trip/trip segment verification.” <http://144.202.240.28/pman/projectmanagement/Upfiles/reports/summary250.pdf>

Contact:  
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Northern Shenandoah Valley Regional Commission  
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For more information:

<http://144.202.240.28/pman/projectmanagement/Upfiles/reports/summary257.pdf>

<http://www.i95coalition.org/PDF/Meetings/EPS/EPS%2008-04-03%20Rural%20ITS%20presentation.PDF>

## **WASHINGTON**

“Washington State passed legislation to institute comprehensive coordination of passenger transportation, and people with disabilities are involved at the top and bottom levels of coordination. The Program for Agency Coordinated Transportation (PACT) and its guiding body, the Agency Council on Coordinated Transportation (ACCT), were created by State statute in 1998. The statute addresses inefficiencies in special-needs transportation and barriers to coordination by establishing the program; creating a strong, representative council; clearly defining its mission and responsibilities; and funding staff. The legislature’s rationale for creating the PACT was “to increase efficiency, to reduce waste and duplication, to enable people to access social and health services, to provide a basic level of mobility, and to extend and improve transportation services to people with special transportation needs.”

“...The legislation mandates levels of coordination at the state-agency level and the local level. State agencies must coordinate policy development, planning, contracting, awarding grants. Local coordination includes a comprehensive community-planning process that focuses on meeting local needs, maximizing the use of all community resources, and implementing efficient operations... The State supports the PACT with funding from the Human Services and Transportation Departments and from the State’s general fund.” (<http://www.unm.edu/~atr/Chapter-5.pdf> p. 122-4).

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## **NATIONAL**

### **Project ACTION**

“Project ACTION (Accessible Community Transportation in Our Nation) is a congressionally created national technical assistance program authorized under the Intermodal Surface Transportation Efficiency Act (ISTEA). The foundational work of Project ACTION is in promoting cooperation between the disability community and transportation industry.”

“Project ACTION maintains a forum as well as a database of transit systems (buses, shuttles, taxis, airport service, etc.) that are accessible for people with disabilities. Using the database is as simple as typing in your destination — for work or pleasure — and seeing the transit opportunities available to you” [http://www.easterseals.com/site/PageServer?pagename=ntl\\_mobility\\_project\\_ACTION](http://www.easterseals.com/site/PageServer?pagename=ntl_mobility_project_ACTION)



**First stop: Hawaii for "People on the Move..."**

"What better time than now to announce that Honolulu, Hawaii, March 15-16 will be the first 2005 place and date for Easter Seals Project ACTION's "People on the Move: Using All Transportation Options (ADA and Beyond...)," the Project's popular bus familiarization training."

"The Hawaii event and four more free train-the-trainer sessions will consist of two days of instruction for travel trainers, teachers, job coaches, bus operators, transportation coordinators, independent living specialists and others who assist people with disabilities in their use of public and private transportation to get to school, jobs and other community destinations" [http://projectaction.easterseals.com/site/PageServer?pagename=ESPA\\_homepage](http://projectaction.easterseals.com/site/PageServer?pagename=ESPA_homepage)

**Supplemental Materials:**

Transportation Solutions for Caregivers: A Solutions Package for Volunteer Transportation Programs [http://www.easterseals.com/site/DocServer/SP\\_order\\_form.pdf?docID=3983](http://www.easterseals.com/site/DocServer/SP_order_form.pdf?docID=3983)

Handbook for Rural Flexroute implementation <http://projectaction.easterseals.com/site/DocServer/00FLEX.pdf?docID=3437>

Serving passengers with cognitive disabilities [http://projectaction.easterseals.com/site/PageServer?pagename=ESPA\\_93SPCD\\_PDF](http://projectaction.easterseals.com/site/PageServer?pagename=ESPA_93SPCD_PDF)

Starting a Voucher Program <http://rtc.ruralinstitute.umn.edu/Trn/TrnManual.htm>



## WAIVER

“The HCBS Waiver has now emerged as the principal Medicaid program underwriting MR/DD long-term care, surpassing Medicaid ICF/MR spending in the states in 2001. The Waiver provides federal reimbursement for a wide array of community services and supports. These include habilitation training, respite care and other family support, case management, supported employment, supported living, various professional therapies, assistive technology, behavior management, and a number of other types of assistance in homelike, community based environments. No state financed all of these options, and there was considerable variability in the services that states opted to fund via the Waiver. The Medicaid Waiver, unlike the ICF/MR program, is a financing vehicle and not a distinct, standardized program” (Rizzolo, Hemp, Braddock, & Pomeranz, 2004) [http://www.cusys.edu/ColemanInstitute/stateofthestates/summary\\_2004.pdf](http://www.cusys.edu/ColemanInstitute/stateofthestates/summary_2004.pdf)

“Under the original legislation, States were authorized to request and provide with Secretarial approval, homemaker/home health aide services, personal care services, adult day health, habilitation, case management, respite care and “other” services requested by the State as the Secretary may approve. Room and Board is specifically excluded except for institutional respite care and live-in personal caregivers. The initial legislation offered home and community-based services to individuals who absent the waiver would require skilled nursing facility or intermediate care facility services including ICF/MR (now Nursing facility for skilled nursing and intermediate care facility services). Subsequent to the original legislation, Congress has: 1) expanded the waiver authority to individuals who absent the waiver would require hospital level of care; 2) extended the renewal authority from three years to five years; ... 4) added, with exceptions, prevocational, educational and supported employment to habilitation services; and 5) included day treatment or other partial hospitalization services, psychosocial rehabilitation services and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness” <http://www.cms.hhs.gov/medicaid/1915c/history.asp>

Some promising Waiver practices in the states include:

- ☐ waiver targeted at individuals with autism (Indiana)
- ☐ waiver incorporating principles of self-determination and consumer direction (Michigan)
- ☐ improved access to services through technology (Ohio)
- ☐ service brokers (Oregon)
- ☐ dual diagnosis (Utah)
- ☐ rebalancing initiative (Vermont)
- ☐ single entry points and person-centered planning (Wisconsin)
- ☐ individualized budgets (Wyoming)



## INDIANA

“The U.S. Centers for Medicare and Medicaid Services (CMS) recently approved changes to Indiana’s Medicaid waiver for persons with Autism and Developmental Disabilities. Under new approved changes:

- Medicaid matching funds can be applied toward an allowance to assist people with disabilities in transitioning from institutional to community settings.
- Allowable transition expenses include apartment security deposits, essential furnishings, and set up fees for utilities and telephones.

Previously, Indiana’s \$1,000 allowance was entirely supported with state funds. Indiana anticipates substantial general revenue cost savings resulting from the CMS approval.” [http://www.nga.org/center/frontAndCenter/1,1188,C\\_FRONT\\_CENTER%5ED\\_5834,00.html](http://www.nga.org/center/frontAndCenter/1,1188,C_FRONT_CENTER%5ED_5834,00.html)

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## MICHIGAN (also Self-Determination, Funding, Consumer Direction)

<http://www.hcbs.org/files/37/1820/miip.htm>

“Michigan has adopted the principles and practices of PCP as the basis for planning and arranging consumer services. However, the adoption of these principles and practices throughout the state has occurred slowly.

This project will expand implementation of arrangements that support self-determination. It will identify and establish system-wide, self-determination options, creating effective and flexible consumer-controlled service arrangements in the Michigan Mental Health system. It will also incorporate the philosophy, information, methods and practices of self-determination, and consumer-controlled options to the MI Choice HCBS waiver system and building in methods to make flexible, consumer-directed options available to beneficiaries who are elderly or disabled. The project will also develop the framework for the approval of a Section 1115 Independence Plus Initiative waiver arrangement, to demonstrate with a limited number of beneficiaries from the mental health and/or the long-term care systems the option of receiving a cash allotment in lieu of formal Medicaid support services.

The project will involve consumers, advocates, and other stakeholders through a project work group, which will guide the project. Specific accomplishments will include: (1) the development of a standardized model for individual budget development and fiscal intermediary services; (2) the development and testing of models for using independent facilitators and support brokers in person-centered planning and consumer-directed care; (3) the development of options for emergency back-



up systems; and (4) the establishment of incident management systems.” <http://www.hcbs.org/files/32/1558/MIip03.htm>

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## OHIO

### **Improving Timely Access to Services (used with elderly population; could be beneficial to DD waiver recipients)**

“A home and community-based services program in Ohio is using electronic communication between case managers and providers to streamline identification of service providers for program participants. Program staff have found electronic communication greatly reduces the time required to find available providers when compared with telephone or fax communication.”

“After the assessment, the case manager sends an electronic notification called a Request for Services (RFS). The case management software system automatically sends the RFS only to providers in the person’s geographic area that offer the services specified in the person’s plan of care. If the person indicates a particular provider is preferred, the case manager sends the RFS only to that provider. If the person does not want service from a particular provider, the case manager can limit the RFS according to the person’s preference. The RFS contains the person’s name and address, the service in the care plan offered by the provider, and other basic information necessary to provide ESP [Elderly Services Plan] services. Providers have 24 hours to respond to the RFS, indicating whether or not they can provide the service” <http://www.cms.hhs.gov/promisingpractices/ohita.pdf>

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**OREGON (also Funding and Consumer Direction)**

[http://arcweb.sos.state.or.us/rules/OARS\\_400/OAR\\_411/411\\_036.html](http://arcweb.sos.state.or.us/rules/OARS_400/OAR_411/411_036.html)

“...Oregon has been implementing a new HCBS waiver that provides in-home and family services through support service brokerages. This program complements its long standing waiver program that offers more comprehensive services to people living in group and foster homes” (<http://www.cms.hhs.gov/promisingpractices/orhcbss.pdf> p. 2).

“Oregon’s Independent Choices Program allows Medicaid-eligible individuals to pay cash directly to providers for personal care and related services. Under this five-year project, participants receive a monthly cash payment and are fully responsible for the mechanics of payroll and budgeting for needed services. An independent evaluation of the pilot project will examine, among other things, whether participant satisfaction and sense of control have increased in comparison to traditional approaches” [http://www.hcbs.org/files/39/1918/OR\\_MaximizingParticipantControl\\_rev.pdf](http://www.hcbs.org/files/39/1918/OR_MaximizingParticipantControl_rev.pdf)

“The Independent Choices Program is, in essence, an experimental offshoot of CEP, which is now part of a Medicaid home and community-based services waiver... As the name implies, CEP places the provider and the person with a disability in an employee/employer relationship. The participant is responsible for hiring, training, supervising, and, if necessary, firing employees. Participants also maintain employee records and sign vouchers for the number of hours worked. Oregon’s Seniors and People with Disabilities Services Division (SPDS) pays providers based on the vouchers.”

“The Independent Choices Program differs from CEP in several key respects. First, instead of using vouchers, SPDS sends electronic deposits to participants’ bank accounts, which they use to pay directly for services. The monthly allocation is based on a functional assessment completed by the local case management staff. Receipt of the cash does not impact any other benefits (such as SSI and food stamps) that are available to the participants.”

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**UTAH****Medicaid Redesign Project Dual Diagnosis Pilot**

“The State of Utah is currently implementing a pilot program now known as Habilitative Options and Medical Excellence (HOME), that provides comprehensive health care management to individuals with mental retardation and mental illness. This is an innovative approach that manages and coordinates the consumer’s medical care, mental health treatment and wrap-around services. Historically, these services have been delivered through separate systems with little, if any, communication among service providers.

The purpose of this pilot is to improve quality and cost effectiveness of service delivery for a population of individuals with a dual diagnosis of mental retardation and mental illness. In this pilot we have integrated Medicaid services, normally provided through multiple entities, under a single managed care option. The target population for the pilot includes children and adults with dual diagnosis who live in Salt Lake County. To participate, individuals must be in the DD/MR waiver and choose to be enrolled in the pilot. The total enrollment in the pilot is limited to 100 individuals until we can validate the quality and cost effectiveness of care.

The University of Utah Neuropsychiatric Institute is the single service provider. Administration of the pilot is through the University of Utah, Health “U”. Enrollment began in August 2000 and there are currently more than 60 individuals served in this pilot.” <http://www.dhs.utah.gov/pdf/TheOlmstead-Plan.pdf>

Utah’s waiver is also known for its flexibility and the broad array of services covered. A copy of Utah’s waiver application and be viewed online at: <http://www.hsdspd.state.ut.us/docs/ddmrwaiver.pdf>

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**VERMONT**

“Several years ago Vermont mounted a multiyear effort to increase the proportion of its long term care spending devoted to home and community-based services. This initiative was triggered by a 1996 law that called for shifting the balance of the state’s long term care spending by reducing the rate of growth for Medicaid nursing home expenditures and investing the savings in home and community based supports. Act 160 established specific targets for the level of savings to be achieved in each of the four years following its enactment. Advocacy organizations, providers, officials of the Department of Aging and Disabilities, and key state legislators joined forces to achieve passage of this landmark legislation. The state was successful. In just six years, the share of



the state's long term care expenditures devoted to nursing facility services decreased from 88 percent in 1996 to 75 percent in 2002. In the process, Vermont significantly expanded community based options, including new residential services, and offered greater opportunities for participants to self-direct their supports. For each of the four years that Act 160's rebalancing benchmarks were in effect, the Vermont Department of Aging and Disabilities was charged with developing a budget proposal that presented recommendations for increased investments in community supports. Using the colloquially called "Act 160 Funds" generated from reducing the projected growth of institutional spending, existing programs were expanded and one-time only awards were made to enhance the capability of particular provider types. In addition, Flexible Funds were awarded annually to local long term care coalitions to fill gaps and test out new program concepts. Although the four year period of mandatory reinvestment has ended, the state has continued to support significant increases in home and community based service programs. <http://www.cms.hhs.gov/promisingpractices/vthcbss.pdf> (pp 1-2).

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## WISCONSIN

<http://www.dhfs.state.wi.us/LTCare/Generalinfo/Index.htm>

Wisconsin's family support program is centered around two components: single entry points and person-centered services.

- "Single Entry Points, which provide persons with a clearly identifiable place to get information, advice and access to a wide variety of community supports; and
- Person-Centered Services, which place participants, not services or providers, as the central focus of funding and service planning" (p. 1).

The goals of the *Family Care* project are:

- "Give people better choices about where they live and what kinds of services and supports they get to meet their needs;
- Improve access to services;
- Improve quality through a focus on health and social outcomes; and
- Create a cost-effective system for the future" (p. 2).

The Family Care program is carried out through the Aging and Disability Resource Centers and Care Management Organizations (CMOs).

"One of Family Care's goals is to improve access to services. Aging and Disability Resource Centers provide a clearly identifiable place organization where the public can obtain information on a wide array of community services available to older persons and persons with disabilities. Although they were established as part of the state's long term care reform initiative, the scope of information and assistance they are expected to address includes such varied areas as transportation, employment, food stamps, home maintenance, and legal problems. Their prevention and early intervention mission



is reflected by community education activities that focus on reducing the risk of disabilities, such as fall prevention and physical fitness programs” (p. 9).

“Persons eligible for Family Care bring to Care Management Organizations a capitation payment that finances supports provided in community, residential, and institutional settings. The Family Care benefit includes supports previously funded by the Community Options Program and several HCBS waivers—all of which had an extremely broad and flexible array of covered services—as well as the Medicaid state plan services of home health, therapies, personal care, durable medical equipment and institutional care. By making CMOs financially at risk for meeting the long term support needs of their members, the state expects that cost incentives will lead them to support enrollees in their own homes as the preferred and most cost effective setting, rather than in institutions” (p. 13) <http://www.cms.hhs.gov/promisingpractices/wifamcare.pdf>

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## **WYOMING (also Funding & Self-Determination)**

<http://ddd.state.wy.us/Documents/doors.htm>

<http://ddd.state.wy.us/Documents/promise.htm>

“Wyoming established individual budgets for its home and community-based services (HCBS) waivers for people with developmental disabilities (DD) to improve equity among waiver participants and increase the authority of the consumer’s service planning team. The state uses a statistical analysis of state historical data on individuals’ needs and services to determine individual consumers’ budgets. State staff report this method of determining individual budgets is widely regarded as fair by program participants, their families, and program providers.”

“Prior to instituting individual budgets, the state used assessment information to divide participants into five individual cost limit levels. Participants within the same funding level could have large differences in needs. For some people, a small change in needs measured by the assessment could lead to a large difference in available funds. As a result, some consumers, families, and guardians complained to state staff or requested more funding.”

“To calculate individual budgets, Wyoming uses a method called DOORS (not an acronym). First, the state identifies factors that influence the level of support a person needs and are consistent with the state’s policy that individual service costs should be independent of provider choice. These factors include living arrangement, work setting, the type of services received in the past, and functional and medical information from the assessment...State data on these factors are included in a statistical analysis (stepwise multiple regression) to calculate the participants’ individual budgets.”

“Wyoming recognizes that the individual budget is not always enough to help the person live safely in the community. A portion of each waiver’s overall state budget is set aside in a reserve fund for people who need more funding than the individual budget formula predicts. The local service planning team can ask state staff to use reserve funds if it believes the person needs more support



than is affordable using the individual budget. Approximately 15% of participants use reserve funds.” <http://www.cms.hhs.gov/promisingpractices/wyib.pdf>

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**Supplemental Reading:**

<http://www.in.gov/fssa/community/bestpractices.html>



## COLLABORATIONS

Systems change in the states is often the result of collaborations between key stakeholders. These can be in the form of collaborations between community organizations, self-advocates, families, professionals, state agencies, universities and others. Below is a sampling of some of the collaborative initiatives in the states.

### **Provider, Community Organizations, Self-Advocates, Families, & Professionals**

Child Care - one-to-one “family specialist” mentors (CA) .....	3
Leadership - participatory leadership training of self-advocates, services providers, parents, professionals and other allies (MN) .....	84
Transition - National Center on Secondary Education and Transition .....	109

### **Families & State Agencies**

Family Support - One-stops for families of individuals with dual diagnosis (ND) .....	50
Family Support - collaborative programs with a cross-disability focus (PA) .....	52

### **DD Council, UCEDD, & P&As**

Family Support - collaborative programs with a cross-disability focus (PA) .....	52
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### **DD Councils, P&As & Self-Advocates**

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### **State Departments**

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statewide collaborative efforts (ME) .....	8
statewide Telehealth Network (NE) .....	66
Employment - Customized Works! (MI) .....	41
Transportation – Inclusive Post-Secondary Education (VA) .....	116

### **Self-Advocates & Families**

Leadership - self-advocates teaching family, friends, and professionals about SA (NC) .....	87
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### **Statewide (Government & Community Organizations)**

Child care - statewide inclusive childcare taskforce (NM) .....	11
Employment - Business Leadership Network (MD) .....	36
Education – Statewide Community Education Network on Disability for adults (MN) .....	26
Transition - centers for independent living and transition (KS) [Also inter-state collaboration] .....	113



**Between Universities**

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**Between Universities and School Districts**

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Leadership - leadership training by self-advocates (National) .....	91
Transition - Computer and networking technologies – “DO-IT” (WA) .....	117